Thesis for doctoral degree (Ph.D.)
2018

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Stockholm 2018

Published by Karolinska Institutet.
Printed by Eprint AB 2018

ISBN 979-91-7831-041-8

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ABSTRACT

Background: Rehabilitation after stroke in Uganda is limited due to poor infrastructure, inadequate number of professionals and the poor socio-economic situation of the people. A sizeable number of patients with moderate or severe stroke are admitted to hospitals for initial care, but the majority do not receive rehabilitation. There is a lack of knowledge about the rehabilitation needs of people with stroke and the lack of culturally adapted assessment instruments to capture the perceptions of the impact of stroke on everyday life among those with stroke.

The overall aim of this thesis was to build knowledge about rehabilitation needs and develop a model for family-centred and mobile phone-supported rehabilitation intervention enabling participation in Activities of Daily Living (ADL) - among people with stroke and their families living in Uganda.

Method: This thesis comprises four studies using qualitative *(Study III)* and quantitative methods *(Studies I, II, IV)*. In Study I, the Stroke Impact Scale (SIS) was adapted, translated and validated during three phases. The data collection involved 25 participants from three expert committees (phase 1), four translators (phase 2) and 95 people with stroke (phase 3). Analysis involved reports from expert committees and validation through use of a Rasch model. In Study II, in a cross-sectional study, data on clinical characteristics was collected from 120 persons with stroke in two separate samples; acute/sub-acute sample (n=58), and for the chronic sample data from the adapted SIS was collected (n=62). Descriptive statics were used to analyse data. In Study III, eleven people with stroke and nine family members were interviewed regarding their experiences of mobile phone use. Grounded Theory approach was used in data collection and analysis. In Study IV, a pre-post design was used, involving an intervention group (n=13) receiving a mobile phone-supported family-centred ADL intervention (F@ce^{TM}) and a control group (n=15). The data was analysed using descriptive statistics.

Results: The SIS 3.0 was culturally adapted and translated into SIS 3.0 Uganda version (Luganda). In total, 10 out of 59 (17%) items in the eight domains were changed. The Strength and Memory domains had all items showing acceptable goodness of fit to the Rasch model. There were more than 5% of person misfits in the domains Participation and Emotion. The domain of Hand function had the lowest proportion of person misfits. Reliability coefficient in all domains was ≥0.90, except the Emotion domain (0.75) *(Study I).* Stroke in Uganda affects a young population with a mean age of 51years. Patients admitted to Mulago Hospital had more severe strokes. In the chronic sample, the SIS 3.0 domains Strength, Hand function and Participation were the most impacted *(Study II).* People with stroke and their family members perceived the mobile phone as a ‘‘life line’’ and extension of the body enabling reintegration into community, belonging, connection and agency to function in and structure a complex everyday life. The mobile phone could be an important tool to improve accessibility and affordability and could be an alternative to basic rehabilitation service after stroke in Uganda *(Study III).* Study IV showed differences regarding perceived self-efficacy and occupational performance in favour of the intervention group. The F@ce^{TM} model was feasible in the context of Uganda, and the effect of F@ce^{TM} needs to be evaluated in a larger study. *(Study IV).*

Conclusion: People with stroke and their family members face a challenging everyday life due to the consequences of stroke and a lack of accessible and affordable rehabilitation interventions. In this thesis, knowledge was generated on cultural adaptation of an instrument for use in rehabilitation after stroke as well as the feasibility of using a mobile phone-supported family-centred ADL intervention for people with stroke. The culturally adapted and validated SIS 3.0 Uganda version is a contextually appropriate instrument that will provide valid measures of perceived impact of stroke. The findings highlight the fact that mobile phones are vital tools, commonly available to people, who can connect clients and families to therapists and thereby promote access to rehabilitation interventions. The F@ce^{TM} model was contextually adapted and was based on personal preferences of daily occupations to regain independence in everyday life which seemed to work with minor technical changes.

LIST OF SCIENTIFIC PAPERS

I. Kamwesiga J, von Koch L, Kottorp A, Guidetti S. Cultural adaptation and validation of Stroke Impact Scale 3.0 version in Uganda: A small-scale study. *SAGE Open Medicine*. 2016;4:1-10.

II. Kamwesiga JT, Eriksson G, von Koch L, Guidetti S. The impact of stroke on people living in central Uganda – a descriptive study. *(Submitted*)

III. Kamwesiga JT, Tham K, Guidetti S. Experiences of using mobile phones in everyday life among persons with stroke and their families in Uganda - a qualitative study. *Disabil Rehabil 2017;39(5):438-449.*

IV. Kamwesiga JT, Eriksson GM, von Koch L, Fors U, Ndiwalana A, Tham K, Guidetti S. A feasibility study of a mobile phone supported family-centred ADL intervention, F@ce^{TM}, after stroke in Uganda. *(Submitted)*

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
AOTA	American Occupational Therapy Association
BI	Barthel Index
CADL	Client-Centred ADL
CAOT	Canadian Association of Occupational Therapists
CG	Control Group
CMOP	Canadian Model of Occupational Performance
CMOP-E	Canadian Model of Occupational Performance and Engagement
COPM	Canadian Occupational Performance Measure
DIF	Differential Item Functioning
F@ce	Face-to-face Assessment Collaboration Evaluation
GT	Grounded Theory
ICF	International Classification of Functioning, Disability and Health
ICT	Information and Communication Technology
IG	intervention group
MOHO	Model of Human Occupation
MRC	Medical Research Council
mRS	Modified Rankin Scale
MnSq	mean square
NCD	Non-Communicable Diseases
NRH	National Referral Hospital
OGQ	Occupational Gaps Questionnaire
OT	Occupational Therapist
RCT	Randomised Controlled Trial
RRH	Regional Referral Hospital
SIS	Stroke Impact Scale
SMS	Short Message Services
SPSS	Statistical Package of Social Sciences
SSS	Scandinavian Stroke Scale
UADL	Usual ADL intervention
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNCST	Uganda National Council for Science and Technology
WHO	World Health Organization

PROLOGUE

I was one of the pioneer locally trained occupational therapists in Uganda. Throughout my training as student, I did not see other occupational therapist working to see how they were professionally practicing Occupational Therapy. During field work placements, we were sent to mainly physiotherapy departments with guidelines on how we should achieve the objectives of the placement, with a focus on occupation and using the Canadian model of Occupational Performance (CMOP) and Model of Human Occupation (MOHO) and the fact that we should use client-centeredness in the therapy. Throughout the training and while working as an occupational therapist, a lot of questions were asked of me to prove how valuable my services as an occupational therapist were, deriving from the culture and background of a society that had never heard or seen an occupational therapist before and having the medical model embedded in them. In order to evaluate my self-worth in the lives of those I served, I adapted a strategy to always reflect on how great a contribution I made to my client's quality of life and how I enabled them. I had my own checklist to each and every client I worked on as their therapist, though this checklist was not standardized. I realized that there is a lot the client expected of me, guided by a medical model that I was not offering and there is a lot that I thought I offered which the client could not see as having value to their life.

During data collection for this thesis research, I met a 65 year-old man with stroke in a physiotherapy clinic where I used to collect data. His name was Chris and he had travelled about 40 km from his home to this clinic with his 23 year-old son as caregiver/family member. He had had a stroke for nine months without attending any rehabilitation services after he was discharged from the hospital. His reason for not attending rehabilitation services was a lack of knowledge about the value of the service and the distance was far from his home as well the cost of hiring the vehicle to visit the rehabilitation clinic. I made an appointment with him to collect data for the study that evaluated the mobile phone supported family-centred ADL intervention (F@ce ^{TM}) after stroke in Uganda. He happened to be in the intervention group that would get SMS reminders every day and phone calls twice a week for eight weeks from the occupation therapist. When we began the assessment, I gave Chris a T-shirt to put on. He had never tried dressing himself independently since he had the stroke. Chris jiggled with dressing himself in a T-shirt and was successful. He became very excited at something he thought he could not perform. He was not able to get out of his house, and all his everyday routines were to be bathed, dressed, be given food and remain in the confines of his house without moving outside. He had paralysis of his dominant right side with the hand

not functional at all, and the right leg was better but could hardly move. During goal setting at his home as part of the F@ce^{TM} intervention, Chris identified three goals as "gardening, praying the Rosary and washing". Throughout the eight weeks of F@ce^{TM} intervention, he was very active, motivated and had a tremendous improvement in the occupational performance of his targets. At follow-up, I was amazed at how much improvement he had within eight weeks with F@ce^{TM} intervention. He did not do only gardening in the compound as we had agreed, but went further in the shamba with his wife. Although the hand paralysis was still a big hindrance to functional performance, he had learned to wash simple clothes. Nor did he stop at the targeted goals meant for F@ce^{TM}; he went further and achieved other personal goals. Chris and his family members were very excited at his improvement in ADL performance. He was now confident to talk to the neighbours and started attending church services.

The big lessons I learned from Chris as an occupational therapist from the above background were that the core attribute in recovery after stroke are individual factors (spirituality), because right from the beginning Chris had intrinsic motivation to improve his level of ADL performance. I also believe that he and his family had tried available medical, spiritual and other interventions, but they did not make much difference in this functional abilities. Also, having purposeful occupations contributed to Chris's occupational performance and engagement. Chris wanted so much to go to his shamba regardless of his limitations, and he made sure that he did what it takes to get there. Occupational performance and engagement contributed to Chris's ability to learn skills of interacting with his environment. After his successful encounter with his shamba, Chris was very eager to continue going there and was pleased to show his neighbours that he had come back to an acceptable life.

It is with Chris's story that I reflect back to the checklist I used make as an occupational therapist to gauge the value of my services to the clients. After Chris was discharged home, the daily use of "medicines" to bring life back failed to bring the quality of life to him and his family members. He did not have peace with himself and consequently with other family members, since he was totally dependent on them for ADL. He regained his sense of self-worth after performing and engaging in occupations of his choice.

INTRODUCTION

The main focus of this thesis is a person whose life has been affected by a stroke and the family member who has been directly involved in the care and rehabilitation of their relative with stroke. This thesis intends to contribute knowledge about the situation and needs of rehabilitation for people with stroke in Uganda. Stroke is ranked the second most common cause of death and the leading cause of disability among adults worldwide (1). Data about stroke and other non-communicable diseases (NCDs) is scarce in most parts of Africa, especially in rural Sub-Saharan Africa. Furthermore, low income countries like Uganda more often prioritize infectious diseases, hence less resources are allocated to stroke prevention and rehabilitation (2, 3). Consequently, there is a critical gap in epidemiological data, policy formulation and political will as regards prevention and control of NCDs including stroke.

Uganda, like any other low-income countries, has limited rehabilitation services for stroke because of too few rehabilitation workers, poor infrastructure, low awareness of stroke rehabilitation, poor health support systems and the poor socio- economic situation of the people. Although there are few rehabilitation centres offering services for those with stroke within Kampala, the capital city, the utilization of rehabilitation services is still low since the majority of the Ugandan population (84%) live in rural areas where medical rehabilitation is almost non-existent (4).

CONCEPTUAL FRAMEWORK

The conceptual framework explains the central theories that supported and informed the studies in this thesis. This conceptual framework is grounded in models and theories of occupational science and occupational therapy.

Occupation in relation to health and well-being

This thesis is about persons who have had a stroke living with their family members in Uganda and their participation in daily occupations in everyday life. The following definition of occupation has been chosen, as it emphasises on the meaning and value in a person's everyday occupations. Furthermore, it acknowledges the importance of environmental and cultural aspects on everyday doing. *"Occupation refers to groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity)" (CAOT, 1997, pp. 34)*

To understand persons experiences after stroke and its consequences in the context of Uganda, the Canadian Model of Occupational Performance and Engagement (CMOP-E) (5) and the Model of Human Occupation (6) have been applied. CMOP-E is characterised by a particular focus on the client's active involvement in the occupational therapy process. In CMOP-E, Townsend and Polatajko (5) presented six basic assumptions underpinning the model, and proposed that "1) humans are occupational beings; 2) occupation has therapeutic potential; 3) occupation affects health and well-being; 4) occupation organizes time and brings structure to living; 5) occupation brings meaning to life through the combination of cultural and individual influences on the creation of meaning, and, as the last assumption, 6) occupations are idiosyncratic" in that the specific occupations that someone might engage in will vary from person to person. The environment could involve physical, institutional, social and cultural components where it could facilitate and hinder occupational performance and engagement in everyday life (5). In this thesis, the cultural influences will be remarked on specifically later in the introduction.

The occupational perspective was based on the Model of Human Occupation (MOHO) (6), as MOHO seeks to explain how occupation is motivated, patterned and performed. According to MOHO (6), many of the activities of human life are taken for granted and are characterized by the fact that they provide structure and meaning to people, which is a basic condition for life itself. The MOHO emphasizes understanding what people do and the meaning of doing in their everyday lives. MOHO is used to explain why problems can arise after stroke, and how the impairments as well as the environmental factors involved can interrupt occupational performance and participation in everyday life. The MOHO has also integrated a client-centred perspective and the concept of the lived body (7, 8), which is in line with the perspective applied in this thesis.

Enabling participation

In occupational therapy, enabling participation in everyday life has been identified as key and an overall goal in the field of rehabilitation (9, 10). Enabling refers to "concepts of giving power, strengthening, providing with the ability or means to do something and with the means to do or be something, and making something possible" (5, 11). The concept of participation is defined in various ways in the literature. Participation is seen by Mallinson and Hammel (12) as the nexus of what a person can do, wants to do and has the opportunity to do and is not prevented from doing. This way of framing participation is in line with how participation in daily occupations can be viewed and is therefore used in this thesis.

Participation is crucial for all humans and has a positive impact on the health as well as well-being of those living with disabilities (13, 14). Participation naturally occurs in everyday life through daily occupations, though it can be experienced differently among individuals within different contexts. There is a strong association between individual interests and participation (9) that seems to explain various levels of experiences across all ages.

However, participation can be affected by what persons do every day, how well they do it, how much they enjoy their doing, their age, family, communities, environmental supports, and disability (9,15, 16, 17). Previous studies suggest that participation restrictions should be understood and measured from the perspective of the individual, and that autonomy is seen as being an important requirement for participation, since it is related to the rights of individuals with disabilities, their empowerment to decide and to have control over themselves and their lives (18, 19). Restrictions to participation may be within a person or external to the person at the family and community levels. Therefore, participation needs to be evaluated continuously during the rehabilitation process, since several personal and environmental factors, including skills and abilities, choice of occupation, cultural practices, communication, problem-solving, decision-making etc. could be affected.

This thesis focuses of participation on both the kind and the magnitude of involvement in everyday life of people with stroke and their family members in order to acquire life experiences, connect with others and build communities, and find a purpose and meaning in life (9).

Daily occupations and participation in everyday life

Townsend, Polatajko together with colleagues have developed a taxonomy (5), where they define and clarify the difference between the concepts of occupation and activity. They frame occupation as “an activity or a set of activities that is performed with some consistency and regularity that brings structure and is given values and meaning by individuals and a culture.” In the same taxonomy, activity is defined as, “a set of tasks with a specific end point or outcome that is greater than that of any constituent task.” Furthermore, occupation among other things gives meaning to life, through helping individuals to learn from the environment, master skills and express their individuality (5). Inability to fully participate in daily occupations has been shown to affect the individual functioning in everyday life. The concept of functioning in everyday life is used in this thesis, and it is in harmony with that of the International Classification of Functioning, Disability and Health (ICF) (13). Functioning

focuses the attention on the positive facets of the interaction between individuals and their contexts in everyday life i.e. participation, activities, body function, contextual factors and health conditions (13, 14).

Hence, life conditions may be changed through participation in daily occupations, since the occupations dynamically integrate the person with the social world (20). Performing daily occupations and enabling supportive contexts may promote the use of self-invented strategies to change life conditions and in turn result in improved possibilities of recapturing occupations in everyday life (21). Occupational therapy "is the art and science of enabling engagement in everyday living, though occupation, of enabling people to perform the occupations that foster health and well-being, and of enabling a just and inclusive society so that all people may participate to their potential in the daily occupations of life" (5).

Agency has been suggested as being an important feature in the performance of daily occupations (22), as it involves choice of what to do and the will and power to perform which affect a person's daily routines (23). This is mirrored in the definition by Aarts et al (24) expressed as "the feeling that one causes one's own actions and their outcomes". Moreover, agency can be viewed as a prerequisite for taking part in various occupations in everyday life.

Occupations in the Ugandan context

Occupations is greatly influenced by physical, social, institutional and cultural environmental demands. Occupational therapy theorists believe that it is through one's occupation that people experience their world in many different ways (25). Occupations and patterns of occupations vary between cultural contexts. In Uganda, a rich diversity of traditions and cultural activities shape people's everyday lives. Since the majority of the population (84%) live in rural and remote areas (26) a large proportion of the people practice farming, run small retail businesses and make crafts. Nonetheless, a lot of attention is paid to the activities of daily living (ADL) in the home environment, since most self-care activities are executed manually such as washing clothes, bathing using a basin, keeping compounds clear of weeds and grass, and sweeping houses. In high income countries, machines and other technological devices are used to accelerate activity completion, thereby allowing more time for other activities. However, in Uganda the majority of the people are mostly engaged in productivity and self-maintenance occupations that fulfil primary physiological, security and belonging needs. Leisure occupations that fulfil part of self-esteem needs and self-actualization occupy less of their time and motivation and, may have an effect on occupational balance (27). In this

thesis, the influence of culture and traditions on the choice of and demands on performing occupations are obvious in all the studies.

Cultural perspectives

Culture and context are significant aspects in this thesis, since values and customs learned within one´s culture affect the beliefs about health and how it is dealt with (25, 28). In Uganda and elsewhere in sub-Saharan Africa, the belief is strong that people relate to nature and supernatural beings and that there are essential connections between the individual and their ancestors' (29). It is believed that any of these connections can be a source of a health problem or disability. Therefore, people will seek health-related help from what they perceive to be the source of their health problems. The strong spiritual tradition that characterizes some individuals' motivation in everyday life is to seek for health and well-being through visiting religious centres or traditional healers' shrines. According to Hammell, culture describes "the knowledge, beliefs, values, assumptions, perspectives, attitudes, norms, and customs that people acquire through membership of a particular society or group" (30). Individuals participate and engage in occupations that embed cultural meaning in the form of values and habits (31). In MOHO, key dimensions of occupational engagement are identified and these include experience of satisfaction/enjoyment with the performance of occupations, the capacity to exercise skills in performance, the use of old habits shaping the performance, the enactment of a role while performing, the meaning of the performance for life, and the feeling of competence in the performance of the occupation (6).

One of the important cultural patterns and values in the context of this thesis is respect for old people, the significance of the extended family and the way these influence the health and well-being of the people (32). For instance, as the young people respect the old people, they must, in return, take care of the younger, give advice and a conducive environment to the latter to realize their full potential. The young in return must provide care when the elder is sick or has limitations in the performance of their daily occupations. The transactional relationship is mutual, and does not encourage independence of the individual's participation in everyday occupations, but rather promotes care and interdependence. This however, contradicts the occupational therapy values and belief which strives to make individuals maximize functional independence in ADL (7). Notwithstanding this, this thesis intended to capture occupationally rooted and context-relevant perspectives in occupational therapy. Thus, this thesis intentionally adapts the relevant contextual elements and concepts as much as possible.

Impact of stroke on everyday life

Stroke is one of the medical conditions classified under the Non-Communicable Diseases (NCDs) that are non-infectious and non-transmissible among humans (33). Stroke accounts for most NCD deaths, followed by cancers, respiratory diseases and diabetes. Noteworthy is the fact that Sub-Saharan Africa has 11% of the world's population, bearing over 24% of global disease burden, but only has 3% of the global health workforce. The increasing burden of stroke brings further challenges to a limited and poorly organized and distributed health care professional. Stroke is defined as "a clinical syndrome characterized by rapidly developing clinical symptoms and / or signs of focal, and at times global (applied to patients in deep coma and those with subarachnoid haemorrhage) loss of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin" (34).

The long-term consequences resulting from stroke are always underestimated and misunderstood (35). Stroke does not only result in long-term disability, but it can have a potential impact on the patient and their family leading to dependency on others for assistance with everyday activities (14, 36, 37). Those people with stroke commonly experience physical role alteration, emotional problems, cognitive impairment and reduced social interaction in the late phases of stroke (38, 39, 40, 41). The impact of stroke might result in participation restriction in various occupational domains such as self-maintenance, social relationships, productivity and leisure. Due to impairments and restrictions in participations, the person with stroke may require permanent or temporary care and help with ADL related to independent living in the home and community (42). The impairments that are visible to others may result in stigmatising social experiences and further lead to post-stroke maladaptation, which is a key barrier to optimal post-stroke outcomes (43). However, stroke affects individuals differently, in that some recover completely though others may be severely affected leading to death or total dependence and still others may have difficulties in resuming a normal level of functioning resulting in a poor quality of life (35).

The impact of stroke can be viewed from various perspectives which overlap: persons with stroke, their families and caregivers, health workers, acute hospitals admissions and policy makers (44). This thesis however focuses attention on only those with stroke and their family members (caregiver). In most cases, researchers, clinicians and others may focus on the visible consequences of stroke, such as a problems with walking, blurry speech and limitation in performance of ADL. The accompanied emotional changes might be more disabling, and such difficulties are exacerbated by being "hidden" to people around them (17). Furthermore,

people's self-esteem and social identity may be worsened by the stigma associated with the new status. Contextually, there is evidence that the stigma felt by those with stroke could lead to participation limitation in everyday occupations (17). There is, however, a lack of empirical research in the area of stroke and especially concerning the consequences of stroke and how they impact everyday life in the Ugandan context.

Family-centeredness

The client-centred perspective is a term that emanated from Carl Rogers (45). In 1997 the Canadian Association of Occupational Therapists defined client-centred practice as collaborative approaches aiming at enabling occupation with clients who may be individuals, groups, agencies, governments, corporations or others (CAOT, pp 109).

In Uganda, the extended family system is interdependent i.e. the state of being dependent upon one another, and provides a sense of security and belonging as well as socialising the individual into the societal system (46, 47, 48, 49). It is difficult to have an individual perspective, since the family needs to been seen as a unit. Previous studies have shown that individuals in traditional societies tend to rely on members of their group for support with psychological, emotional and socioeconomic issues (50). Family cooperation and engagement might be one indicator of successful rehabilitation after stroke, since such support mitigates the potential negative physical and emotional health consequences. A supportive family could potentially improve the psychological outcome and functional status of persons with stroke and their family members (51).

Levack and colleagues have shown that the family members' involvement in goal-setting clarified their expectations and assisted in their setting realistic targets as well as supporting the implantation of targets (52). There is no established definition of family, because how a family is seen is constantly changing and extends depending on how people view themselves and others in relation to what is commonly referred to as a family. Thus, a definition of family is based on structure, relationship and residence (53).

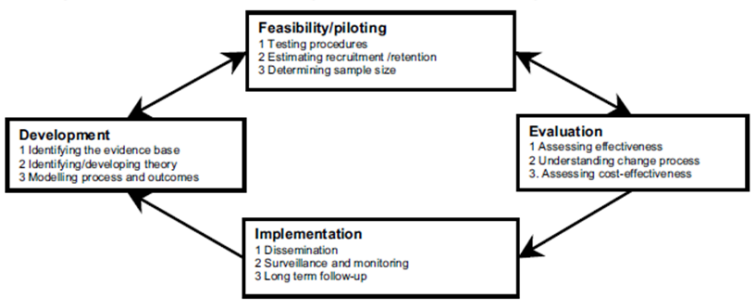
Providing care is always demanding, due to the complex nature of the consequences and limited preparation for caregiving tasks in the families resulting in experiences of adverse effects on the stroke survivor's physical and emotional health, social activities, financial situation and spiritual functioning (42, 54, 55). For a successful health outcome among those with stroke, family members are an important resource and a more worthwhile use of health and social service resources (56). Family members play a vital role in stroke recovery and rehabilitation, enabling many of those with stroke to have an acceptable quality of life and

remain living in the community (57). Due to stroke, family members could suffer from depression and anxiety, family tensions and financial problems (58, 59). It is imperative that the family members access useful information and advice about the care and rehabilitation of a person with stroke and receive skills training, emotional support and regular relief. Lack of multidisciplinary models of care seem to increase family members' burdens. In addition, family members' burdens increase when responsible agencies fail to supply promised aids or services, and when there is a lack of support groups for patients and their careers (44, 60). It is well-known that members in families support one another and take huge responsibilities for care when needed. However, knowledge is lacking regarding the family as a unit in connection with taking part in rehabilitation after stroke.

Complex interventions within rehabilitation

In this thesis, the Medical Research Council (MRC) (61) recommendations in the guidelines for developing and evaluating complex interventions has been used. The term complex interventions is widely used in the health care service, in public health practice, and in areas of rehabilitation. Complex interventions are often described as interventions that contain several interacting components, but they also have other characteristics that the evaluators need to consider. What makes an intervention complex is i) the number of interacting components within the experimental and control interventions, ii) the number and difficulty of the behaviours required by those delivering or receiving the intervention, iii) the number of groups or organisational levels targeted by the intervention, and finally iv) the number and variability of outcomes as well as the degree of flexibility or tailoring of the intervention permitted (61, 62).

Figure 1 Key elements of the development and evaluation process



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Developing and evaluating a complex intervention is a process with several phases, but might not follow a linear sequence. First, the existing evidence and knowledge gaps in the area of research need to be clarified and the theoretical framework outlined. In the next phase, these theories are applied to serve as a platform for the development of the new intervention. In this thesis, the intervention used in Uganda was modelled from the rationale and content of the Swedish client-centred ADL (CADL) intervention (63, 64). The CADL intervention was mainly based on a series of qualitative research studies aiming to better understand the lived experience of everyday life after stroke by using the client's lived experiences as the starting point for the intervention. Finally, in this thesis, a piloting of the test of the newly modelled intervention needed to be done (Study IV) before a full-scale evaluation with a Randomised Controlled Trial (RCT) and implementation can be conducted.

The health system and the structure of health care delivery in Uganda

The health care service delivery in Uganda is regulated by the government and supported by the private sector (65). The Ministry of Health is responsible for planning and allocation of finances to the health units. The private wings of public hospitals and health care at private health facilities are financed by out-of-pocket payments from the patients (65).

Health care services are delivered at specialized tertiary level by the National Referral Hospitals (NRHs), and at a secondary level by Regional Referral Hospitals (RRHs) with narrower specialisation. Primary services in communities are provided by health centres or Village Health Teams. The health centres are graded between one and four depending on the level of care provided. The private health care system is responsible for about half of health care service delivery, and private providers include private not-for-profit practitioners, as well as practitioners from the private health care and those that practice traditional and complementary medicine (65). Furthermore, medical rehabilitation services including physiotherapy and occupational therapy are to a large extent provided by private for-profit practitioners, but also by NRHs, RRHs and non- governmental organisations.

Despite the fact that a great percentage of the households (72%) live within a radius of five kilometres of a health care facility, limited utilisation of these health facilities has been reported. This is related to factors such as a lack of transport to the facilities, poor infrastructure, shortage of medicines/medical supplies, human resource shortages attributable to low wages, lack of accommodation and incentives for the staff (65). So, even if the

majority of the population in Uganda live in rural areas, they may not access basic health care since there are no health care financing schemes available to them.

The relationship between being poor and having access to health care services can be seen as part of a larger picture, where poverty hinders accessibility and affordability of basic health care. Despite the elimination of user-fees by government, in public health care units the out-of-pocket costs still are high. Therefore, financial accessibility has persisted in being a challenge and cannot be managed for the majority of the population. For those with stroke it has been a major challenge to access rehabilitation interventions, since the family must provide all the required resources without any assistance from anyone. Women continue to face the majority of caregiving responsibilities simultaneously for their children and their parents. This intergenerational care places increasing pressure on the home care system that women anchor. In order to develop relevant rehabilitation interventions, there is a need to understand the cultural context as well as the health and social support systems in Uganda.

Uganda is a member of United Nations and was among the first countries to develop a national development plan according to the Sustainable Development Goals' (SDGs) agenda (66). According to SDGs, health and well-being are central concepts, and Goal 3 is particularly dedicated to health and aims to *"Ensure healthy lives and promote well-being for all at all ages",* but also contributes to and benefits from progress on other goals. Health targets are therefore distributed across all goals, and the integrated nature of the SDGs provides new legitimacy for addressing the wider determinants of health. The SDGs also explicitly include disability and are referenced in multiple parts, specifically in the parts related to education, growth and employment, inequality, accessibility of human settlements. Uganda has well formulated policies especially about the health care system but these policies are seldom implemented for the benefit of the people (67). Implementation of these policies is needed and also subsequently evaluated in the area of rehabilitation after stroke.

Rehabilitation after stroke

In order to develop a relevant intervention for persons with stroke, there is a need to understand how effective rehabilitation services should be organised. In 2001, WHO described rehabilitation after stroke as a health procedure that "aims to facilitate people with stroke who are likely to experience disability to attain optimal functioning in interaction with the environment" (68). In other words, it is an umbrella term for several services aimed at aiding people with disabilities to improve their physical, psychosocial, and vocational potential to alleviate physiological and environmental limitations (69). After stroke, several

aspects influence how an individual experiences a life-course disruption. Recovery after stroke is often a long and demanding process. However, the stroke rehabilitation programme remains an essential component in the recovery, and it is recommended that it should start as early as possible to avoid potential complications (70). There are studies that recommend an ADL-oriented approach in rehabilitation after stroke rather than a theory-based, impairment-oriented approach (71). In Scandinavia it is recommended to stay in a stroke unit rather than on a general medical ward during the hospital stay to make a good recovery (72). Recommended effective rehabilitation interventions after stroke are built on evidence obtained for groups with various impairments, on isolated variables, identified as significant for recovery. Various approaches may be used in rehabilitation after stroke which may not reverse the effects of a stroke, but may help the person to learn strategies to re-establish their confidence and abilities (38). The ability to perform daily occupations is often used as a measure of functioning after stroke (70). There are, however, no existing clinical guidelines for rehabilitation of people with stroke in Uganda.

A client-centred rehabilitation has been recommended for use in rehabilitation after stroke (73) since it empowers the clients to be active and fulfil their vital life goals, as well as achieving an optimal degree of social well-being and functioning (74, 75). Family cooperation and involvement in the rehabilitation after stroke has been recommended since it alleviates potential negative physical and health consequences (49) and the family-centred perspective will be used in this research.

Mobile Technology and Health Systems Strengthening

In this thesis, mobile phone technology was explored to establish whether it could be an affordable and accessible alternative to rehabilitation services after stroke in Uganda. The shortages of health care professionals, lack of resources, inadequate knowledge about the value of rehabilitation and poor social economic situation of the people hinder the performance of health workers. The Ugandan health system faces far-fetched challenges in responding to the needs of the population since the majority (84%) of the population lives in rural areas (76). However, new ways of providing health care services including rehabilitation might create a sustainable solution to tackle part of these problems. Mobile phones have been rapidly integrated into everyday life in East African countries (76). In 2016, there were 420 million unique mobile subscribers in sub-Saharan Africa with a penetration rate of 43%, and it is expected to reach a penetration rate of 74% by 2020 (77). In this thesis, mobile phones were considered as a part of information and communication

technology (ICT) as being "forms of technology that are used to transmit, process, store, create, display, share or exchange information by electronic means"(UNESCO)(78).

The integration of ICT and specifically the use of mobile phones into the daily lives of individuals is growing worldwide. The enormous variety of smartphone and tablet applications could be used in new innovative ways to support peoples' everyday lives through activities such as communication, gaming and reading newspapers, thus leading to a rapidly increasing societal demand for ICT use (79).

The potential of using different ICT solutions among stroke survivors is supported by previous studies (80, 81, 82). For example, some studies conducted in high-income settings suggest that ICT can be used as a tool for communication between health care professionals and clients in home care, promoting self-care and improving the performance of ADL for people with stroke. Therefore, the use of ICT in health care services is seen as having the potential to increase accessibility and continuity in service delivery, and can be considered as a means of strengthening the health system (83). However, to ensure the efficiency and sustainability of ICT based services, these should be integrated into the local context with consideration (83). Hence, conducting research in this area was motivated by the knowledge gap related to the needed actions, processes and resources enabling a successful integration of mobile phone-based health services in Uganda.

Mobile-phone use in rehabilitation

In this thesis, the ICT technology used was mobile phones. A mobile phone can be understood as a basic simple telephone that one can carry and use to make or receive calls wherever you are. After observing that almost every adult person in Uganda carried one or two mobile phones and most of the time people were using them to communicate with each other, it qualified the assumption that they could be a good alternative to use in rehabilitation after stroke in Uganda. Other studies have indicated that tele- rehabilitation can provide an equally effective means for rehabilitation compared to conventional rehabilitation methods, or can be used as complementary services (84). The term 'tele rehabilitation' refers to any ICT-supported rehabilitation services provided for people in their homes or other environments due to long distances to health care facilities (85, 86). Furthermore, until today no literature is available on studies of the use of tele rehabilitation in stroke care in low-income settings such as Uganda.

Mobile phone technology provides both the capacity and an attractive media option to support family-centred home-based occupational therapy intervention. The client with mobility restrictions, economic challenges and long distances away from occupational therapists, can access the rehabilitation interventions at an affordable cost (87, 88). Mobile phone devices have the most extraordinary feature and capability to communicate and transfer information between both literate and illiterate individuals. This technology has accessed a significant proportion of the general public due to the fact that mobile phones are cheap to buy and operate. One of the previous studies (89) has showed that mobile phone users shared their mobile phones with others who did not have one, hence extending their health and connection-related benefits even farther (89). Increasingly, people have mobile phones on as a way to assure that they can be safe and secure (90). Mobile phones are also handy from the healthcare service provider's perspective, since they have the capacity to distribute multimedia communication and information for feedback to individuals. However, to ensure the efficiency and sustainability of mobile-based services within rehabilitation, they should be integrated into the local context with consideration (76).

RATIONALE FOR THIS THESIS

Non-communicable diseases are increasing in sub-Saharan Africa, of which stroke accounts for most deaths. The Ugandan health care system does not prioritize the rehabilitation of NCDs. There is a lack of research on stroke rehabilitation and specifically a lack of knowledge among rehabilitation practitioners as well as among the families that are affected by a stroke. Furthermore, there is a lack of information on the incidence and prevalence of stroke and clinical guidelines. Resources in rehabilitation staffing and health care resources in general are scarce, which implies a need for developing affordable and available tools already embedded in people's everyday lives.

Research in high-income countries has shown that intervention focusing on ADL is effective, but also that the interventions used should be goal-directed and occupation-based built on an individual's own perspectives of what is important to them. In guidelines world-wide, it is recommended to begin rehabilitation early, and there is need of rehabilitation even in the long term. It is also known that in the cultural context of Africa the family perspective is pronounced and the family is involved in the care. Furthermore, the region of Sub-Saharan Africa is the fastest growing mobile phone market in the world. The coverage of the mobile phone network is extending continuously throughout the whole of Sub-Saharan Africa, and a

potential exists for the delivery of health care and rehabilitation interventions by using mobile phones.

Accordingly, in this cultural context, there is a knowledge gap regarding the impact of stroke, the needs of rehabilitation interventions and how such services should best be organised in Uganda in order to meet the needs of those with stroke and their family members. Additionally, there is a lack of culturally adapted assessment instruments to assess the impact of stroke in the Ugandan context. What is more, knowledge is needed on how mobile-phones, as already in use in the majority of families, can be used as a tool in rehabilitation. Moreover, there is a need to know whether a client-centred ADL-intervention developed in Sweden can be adapted to and be viable in the Ugandan context.

AIMS

The general aim of this thesis was to build knowledge of the rehabilitation needs and develop a model for family-centred and mobile phone supported rehabilitation intervention, enabling participation in Activities of Daily Living (ADL) among people with stroke and their families living in Uganda.

The specific aims were

To culturally adapt the SIS 3.0, translate the SIS 3.0 Uganda version into Luganda, and determine the psychometric properties for each domain scale of the culturally adapted SIS 3.0 Uganda (in English and Luganda) on a small scale. *(Study I)*

To explore and describe the clinical characteristics and functioning during the acute/subacute phase and the chronic phase as well as the impact of stroke on everyday life during the chronic phase in stroke survivors in central Uganda. *(Study II)*

To describe the experiences and meaning of using mobile phones in everyday life after stroke among persons with stroke and their family members. (*Study III)*

To evaluate the feasibility of: i) a mobile phone supported family-centred intervention (F@ce^{TM}), and ii) the study design for evaluating the effects of the intervention on the perceived impact of stroke, perceived participation in everyday life, and self-efficacy in everyday activities among persons with stroke and their families in Uganda. *(Study IV)*

METHODS

STUDY DESIGN

The research focus in this thesis was, using both qualitative and quantitative methods, to develop a rehabilitation intervention for people living with the consequences of stroke in Uganda. Therefore, there was a need first to culturally adapt and evaluate SIS 3.0 instruments in Study I. The instrument was then used to explore the impact of stroke on everyday life (Study II). In order to develop a culturally relevant rehabilitation intervention, the experiences of the people with stroke and of family members using a mobile phone was explored in Study III. The knowledge was further used in Study IV to develop a family-centred and mobile phone-supported ADL intervention for people living with the consequences of stroke and evaluated. An overview of the studies and methods used is given in Table 1.

Table 1. Overview of the studies included in this thesis

	Study I	**Study II**	**Study III**	**Study IV**
Design	Cross-sectional	Cross-sectional descriptive	Qualitative Grounded theory	Controlled pre-post
Participants	N = 95	N =120	N = 20	N= 30
Data collection	Reports and notes from expert committees	Face-face-interview with self-reported instrument	In-depth interviews and observation	Face-face-interview with self-reported instrument
Analysis	Descriptive summaries, translator reports, and Rasch model	Descriptive statistics	Constant comparative Grounded Theory	Descriptive statistics Mann-Whitney U-test
Study context	Admission facility, Rehabilitation facility, Participants home	Admission facility, rehabilitation facility, participants' home	Participants home	Admission facility, Rehabilitation facility, Participants home
Focus	Cultural adaptation, translation and validation	Clinical characteristics and perceived impact of stroke	Experiences of mobile phone use by people with stroke and their family members	Feasibility of study design and of mobile phone-supported rehabilitation after stroke

PARTICIPANTS

The different study groups are presented in Table 2.

Table 2 Overview of the participants' characteristics in this thesis.

Variable	**Persons with stroke**			
	Study I	**Study II**	**Study III**	**Study IV**
Participants with stroke	n = 95	n =120	n = 11	n= 28
Sex Male/Female	45/53	51/69	6/5	7/21
Age, years Mean, (range)	52.4 (16 – 75)	50.0 (16 –75)	47.9 (25 – 75)	60.0 (38 – 75)
Recruitment sites	1) Mulago National Referral Hospital neurology ward 2) Mulago physiotherapy outpatient clinic 3) Stroke rehabilitation centre 4) Participants' homes	1,2,3 same as Study 1	Participants' homes	1, 2, 3 same as Study 1 4) Nagulu Hospital outpatient clinic 5) Participants' homes
Inclusion criteria	1) Stroke diagnosis recorded in medical records confirmed by computed tomography (CT) scan or clinical assessment 2) Absence of psychiatric diagnosis and symptoms identifiable in the medical notes 3) <75 years of age 4) Ability to express self in English or Luganda 5) Living in Kampala and surrounding areas < 40 km 6) Needed assistance in at least two ADLs evaluated by Barthel index	1, 2, 3, 4, 5 same as Study I 6) Admitted to the neurology ward, receiving treatment for acute stroke sample 7) 3 months since onset, but less than 3 years post stroke for the chronic sample	1, 2, 3, 4, 5, 6, same as Study I 7) More than 2 months and less than 3 years post-stroke 8) Used and owned a mobile phone before and after stroke 9) Ugandan citizen	1,2,4,5 same as Study I 3) >18 years of age 6) Access to and ability to use a mobile phone 7) Modified Rankin Scale score 2–4
	Other participants			
Other participants	OT-students n= 15 OT teachers n=4 OT clinicians n=10 Translators n=4 (expert groups)		Family members n=9	Family members n=17
Male/female	23/6	NA	1/8	4/13
Inclusion criteria	OT-students in the OT program, OT teachers in the OT programme Senior OT clinicians Professional translators	NA	1) Primary significant other living with the person with stroke. 2) Ability to understand and respond to instructions in English or Luganda. 3) Used and owned a mobile phone	Same as in study III

NA= not applicable

The participants in studies I-IV

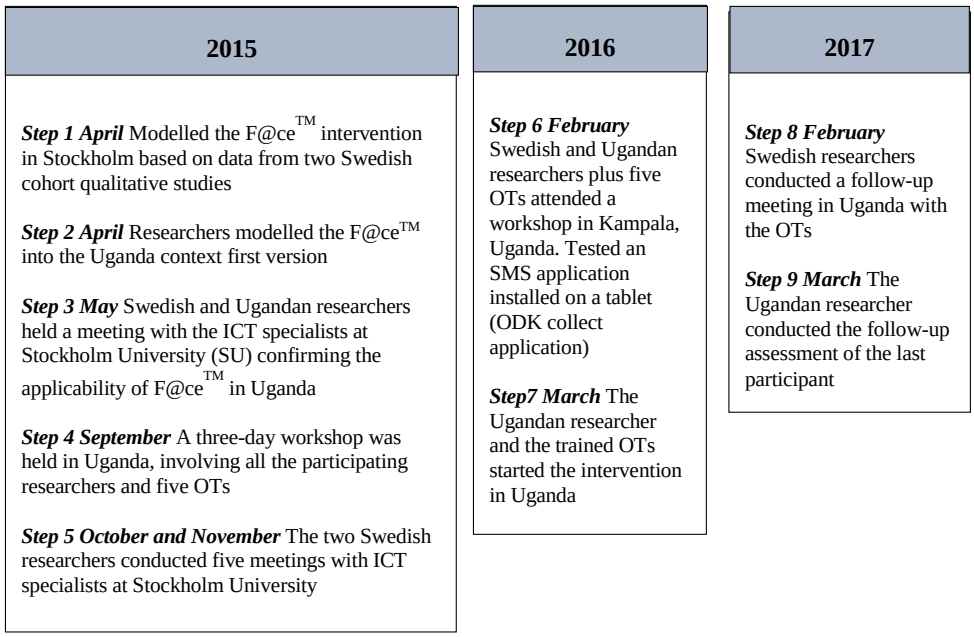
In this thesis, all four studies involved participants with stroke. The sample sizes and characteristics are shown in Table 2. However, all participants in Study III were part of Study I, and the acute/subacute sample of Study II was selected from study I. All those people with stroke in the different studies were recruited from different health units. The people with stroke were asked to identify a family member, e.g. a close relative, to participate in Study III and IV. All those who were considered and subsequently participated in the studies were first asked whether they would like to be involved. Upon accepting they were informed verbally and in writing concerning their participation. The inclusion criteria for other participants *(without stroke)* is shown in Table 2 above.

Planning and modelling the intervention in Study IV

The planning and modelling of the intervention used in Study IV followed the MRC guidelines (61). The process was initiated by a focus group interview with occupational therapists (OTs) and physiotherapists in 2014, which explored the possibility of using mobile phones for rehabilitation in the Ugandan context. The different steps in the modelling process are shown in Figure 1.

A subsequent series of meetings and workshops for modelling the components from a Swedish client-centred activity in the daily living intervention (CADL) (63, 91) model took place both in Sweden and Uganda with researchers, OTs and information communication technology (ICT) technicians. The intervention was tailored to local concepts, preferences, and expressions in order to achieve a good fit with existing practices and values, e.g. family-centred intervention, cost-free, use of participants' own ordinary phones, easily accessible, low cost, and likely to be sustainable. Thereafter, the local OTs who were to deliver the mobile phone supported family-centred ADL intervention (F@ce^{TM}) participated in a preparation of eight half days. In the workshops, the OTs discussed and reflected on the theory underpinning the intervention together with the three of the researchers, the study procedure and the technical modalities of the intervention in relation to the local context.

Figure 1. Timeline of modelling and conducting the intervention



The F@ce™ intervention

The matrix below defines the term F@ce™ and shows how the step-by-step process of the mobile phone-supported family-centred intervention was conducted in Uganda for the intervention group (IG). The superscript TM means the trade mark for the model that was designed by the research group.

Figure 2: The Matrix showing the F@ce™ Intervention

	Intervention	Activity for the client	Activity for the therapist	Activity for the researcher
F **Face-to-face meeting at hospital/ clinic (Before week 1)**	First meeting client, family member and OT. Create a relationship. Planning for next session.	Signs the consent form. Performs according to mRS. Provides contact details.		Screen client using inclusion criteria Explain to the client the purpose of the contact. Sign the consent form. Make appointment with client and OT for baseline assessment and intervention Fill out the demographic protocol and mRS
@ **Assessments 1st visit at home (week 1)**	Involve family members. Train the use of mobile phone. Try out an activity such as putting on a t-shirt. Choose 3 activities Use the COPM. Video tape one activity.	Involves the family member. Tries to send and retrieve a text message (SMS). Calls someone Chooses 3 activities according to COPM. Practices the activity performance, Practices scoring of the activity Performs baseline assessment using Demographic protocol, SSS, BI, SIS, Self-efficacy, OGQ	Grades the activity, identifies the level of performance Involves the family members Demonstrates scoring of activity using COPM	Updates information of the client if needed. Observe performed activities Video tape activities Uses COPM to assess the client level of performance and satisfaction on the 3 activities. Collects data at base line using Demographic protocol, SSS, BI, SIS, Self-efficacy, OGQ.
C **Collaboration (From week 1 – week 8)**	TARGET-PLAN-PERFORM-PROVE as a problem--solving strategy. Perform the 3 activities using the strategies for 8 weeks. Reminders with text message. Activity tracking by text message and calls from OT. Family member involvement	Formulate the targets and add strategies together with OT Involve the family member Practices and performs the agreed 3 activities using the strategies. Receives reminders of the targets every morning and evening. Grades the 3 different activities using a predesigned scale (0–5). Responds to the evening reminders by sending the rated score to a server.	Introduces a problem-solving strategy i.e. TARGET-PLAN-PERFORM-PROVE on the 3 chosen targets. Identifies the strategies. Calls the client 2 times a week for eight weeks. Receives text message from the server if the client scored 0. Calls the client the following day when receives red flag on his/her phone Writes field notes whenever communicating with client.	Demonstrates to the client self-scoring of 3 different activities using a predesigned scale from (0 -5). Hands over the scale to client to be used during 8 weeks of intervention Uploads OT and clients telephone contacts to the server in order to initiate connection between the two. Sends Airtime every day to clients to send text message with rated scores to the server. Collects data from activity tracking Makes an appointment for follow-up assessment. Write field notes. Monitors client text message activities on the serve
E **Evaluation (8th Week)**	Perform and evaluate the TARGETS with COPM.	Performs activities again to identify the difference in performance and satisfaction.		Fill out follow-up assessment protocols. COPM, SSS, BI, SIS, Self-efficacy, OGQ Videos tape the activity when performing.

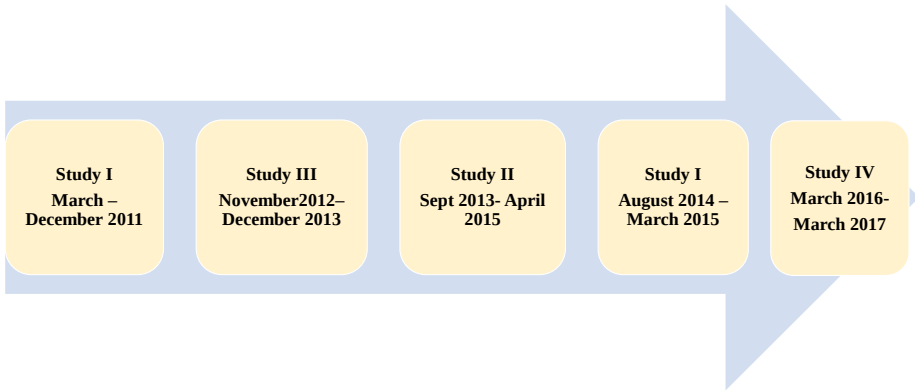
Ordinary rehabilitation

The control group (CG) in Study IV did not receive text messages (SMS) and phone calls, but received ordinary rehabilitation available in the society.

DATA COLLECTION

The data collection in the four studies took place at different periods as indicated in Figure 3 and the different recruitment sites are given in Table 2.

Figure 3. Data collection timelines



Data collection – Study I, II and IV

In Studies I, II and IV face to face interviews were conducted using developed protocols including self -reported instruments (see Table 3). The data collection involving people with stroke in Studies I, II and IV used the SIS 3.0 Uganda version that was validated in Study I.

Study I employed three different phases. ***Phase One*** (cultural adaptation) focused on the cultural adaptation of SIS 3.0 through instrument review by three different expert committees which explored the relationship between the target instrument and the underlying concepts (92). The notes made by each committee formed the basis for data collection.

Phase Two involved the forward–backward translation of SIS 3.0-into the SIS 3.0 Uganda version. This phase involved four translators, two who carried out the translation from English to Luganda and then two translators who carried out the back translation from Luganda to English. The translation reports formed the basis for data collection. The instrument was pretested by interviewing five people with stroke so as to determine the clarity of the item wording.

Phase Three (psychometric measurement) involved administering the culturally adapted SIS 3.0 Uganda (in English and Luganda).
In Study IV, data collection was performed after screening of plausible participants using the Modified Rankin Scale (mRS). Data collection was carried out during a home visit one week after meeting the participant at the physiotherapy clinic, or two months after, if the participants were first met in the acute neurology ward. Names and mobile phone numbers

of participants were made anonymous by assigning them codes. The instruments used in Study IV were installed on a tablet in an application called Open Data Kit collect (ODK) (https://opendatakit.org/about/full).

Interviews with persons with stroke and family members in Study III

In Study III, data was collected by using a semi-structured interview guide including open-ended questions. The interviews were conducted in both English and Luganda in the participants' homes and lasted for 45 minutes to 90 minutes. All interviews were recorded digitally and transcribed verbatim. The interview questions focused on how the participants experienced the use of mobile phones in their daily life. The participants were asked to describe, as concretely and in as much detail as possible, their experiences of using a mobile phone during a typical day after stroke. Field notes were taken immediately after the interviews and served as the basis for the upcoming interview used in the data analysis (93, 94).

Instruments

Data was collected at baseline and follow-up by instruments validated for people with stroke that included: Scandinavian Stroke Scale (SSS), Barthel index (BI), The Stroke Impact Scale 3.0 (SIS), Canadian Occupational Performance Model (COPM), Self-efficacy scale, and Occupational Gaps Questionnaire (OGQ).

Table 3 An overview of instruments applied in Studies I, II and IV

Instrument	Study I	Study II	Study IV
Modified Rankin Scale (mRS)			x
Scandinavian Stroke Scale (SSS)	x	x	x
Canadian Occupational Performance Measure (COPM)			x
Self- efficacy scale			x
Stroke Impact Scale (SIS)	x	x	x
Barthel Index (BI)		x	x
Occupational Gaps Questionnaire (OGQ)			x

Modified Rankin scale (mRS) was used to assess the participation level of those people with stroke in order to qualify them for inclusion in Study IV. The mRS assesses the participant's level of disability and dependency in ADL after stroke. The mRs levels= 0) no symptoms, 1) no significant disability, despite symptoms – able to perform all usual duties and activities, 2) slight disability – unable to perform all previous activities, but able to look after own affairs without assistance, 3) moderate disability – requires some help, but able to walk without assistance, 4) moderately severe disability – unable to walk without assistance and

unable to attend to own bodily needs without assistance, 5) severe disability – bedridden, incontinent, and requires constant nursing care and attention, 6) dead.

Scandinavian Stroke Scale (SSS) was used to collect clinical characteristics, assess neurological impairment and define stroke severity in Samples I, II and IV. SSS is used to a great extent in clinical trials and has been shown to have high inter-observer reliability (0.93) and high concurrent validity (0.94–0.98) especially when performed face-to-face (95). The SSS scores range from 0 to 58 points, where 0 is severe and 58 is the total score (96).

Canadian Occupational Performance Measure (COPM) was used a primary outcome in Study IV and measures performance and satisfaction in self-care, productivity and leisure from the client's perspective, using a scale of 1 – 10. COPM relies on the clients being able to identify their own areas of difficulty (10). The client is asked 1) to rate performance of the specified activities using a 1 to 10 scale, and 2) to score their satisfaction with that performance using the same scale. Weighted scores of the chosen activities are added separately for performance and satisfaction in order to generate two summative scores. The summative scores are then divided by the number of rated activities so as to provide COPM scores that can be used to compare performance and satisfaction over time. A change of two points in the score is seen as a clinically significant change (97).

Self-efficacy scale was used as primary outcome in Study IV. Self-efficacy is based on social cognitive theory Bandura (98, 99), and evaluates the individuals' belief in his/ her capability to perform activities to realise a desired result. The theory of self-efficacy suggests that the stronger person´s efficacy expectations, the more probable it is that they will initiate and continue with given activities. To complete the self-efficacy measure, participants were instructed to rate how confident they felt about performing each of the 16 everyday activities on a 10-point rating scale ranging from 1) "not being confident at all in my ability" to 10) "being very confident in my ability". The Self-efficacy scale used was adapted for people with stroke (100).

The Stroke Impact Scale 3.0 (SIS) Uganda version was used in Studies I and II and as a primary outcome in Study IV. The SIS 3.0 Uganda version assesses the perceived impact of stroke within eight domains; Strength, Hand function, ADL/Instrumental activities of daily living (IADL), Mobility, Communication, Emotion, Memory and Thinking, and Participation (101). Each domain contains four to ten items that are rated on a five-grade scale. The SIS 3.0 Uganda version also comprises a stroke recovery-scale on which the client is asked to indicate how much they have recovered from 0 (not recovered at all) to 100 (fully recovered);

the higher the score, the lower the perceived impact of stroke, i.e. fewer problems in everyday life.

Barthel index (BI) was used in Study II and as a secondary outcome in Study IV. BI assesses the level of dependence in ADL in study II and IV (102). The BI has a high level of reliability and validity when used with samples of people with stroke (35). The BI has been shown to be sensitive enough to detect when someone starts to need assistance, which is of great clinical relevance (103). Each item in BI is given a score of 0, 5, 10 or 15, and the item scores are summarised to give a range of scores from 0 (totally dependent) to 100 (totally independent). ADL abilities were evaluated by identifying the total score of BI and then classified into three categories; Independent (91–100), with help (60–90) and dependent (≤59).

Occupational Gaps Questionnaire Ugandan version (OGQ-U) (104) was a secondary outcome in Study IV. OGQ is a self-reported questionnaire measure of the extent an individual performs activities they want to perform, and the extent the same individual does not perform activities they do not want to perform. It is used to gather information about and understand the client's situation with respect to daily occupations. There were two questions connected to each activity. The questions were "Do you perform the activity now"? and "Do you want to perform the activity now"? If someone responded "yes" or "no" to both of these questions, then there were no occupational gaps, but if the response was "yes" to one of the questions and "no" to the other, this was considered to be an occupational gap (15).

DATA ANALYSIS

Analyses in Studies I, II and IV.

Adaptation and translation process of SIS

Study I involved cultural adaptation and translation of SIS 3.0 into SIS 3.0 Uganda (both English and Luganda versions) with permission from Mapi Research Trust, and followed the recommended procedure for cross-culture adaptation of self-report measures (105). In Phase One, the comparisons were guided by the four principles: experiential equivalent (do the words used capture an experience of daily life in the target culture?), conceptual equivalence (some words hold different meanings between cultures), semantic equivalence (do the words mean the same thing?) and idiomatic equivalence (words that are difficult to translate require an item with a similar meaning) (105).

In Phase Two, the reports from translators with the main components were analysed under the themes semantic experiential, idiomatic, and grammatical use of words. Furthermore, the SIS 3.0 Uganda version-Luganda was checked for spelling errors. The evaluations from the

pre-tested instrument were discussed in order to ensure the expressions and their cultural relevance were valid.

In Phase Three the adapted and translated SIS 3.0 Uganda versions were tested statistically, described as followed.

Statistical Analyses

Descriptive statistics were used to describe the samples regarding demographic and clinical characteristics, functioning and perceived impact of stroke in Studies I, II and IV.
In Study IV, the calculated differences in scores between baseline and follow-up were compared using Mann-Whitney U-test for the ordinal data. The significant level in Study IV was $P< 0.05$, and the analyses were conducted using the Statistical Package for the Social Sciences (SPSS).

A Rasch analysis was used in Study I (Phase Three) to test whether the items in the adapted and translated SIS 3.0 Uganda version could generate valid measures of the various constructs. A Rasch analysis converts the raw item scores from the SIS 3.0 Uganda version into equal-interval measures or logits (log-odds probability units) using the WINSTEPS software program (version 3.69.1.16). In the Rasch analysis the rating scale functioning, internal scale validity and unidimensionality, person response validity, differential item functioning (DIF) and person separation index were evaluated for each construct.

In order to meet the essential criteria for the measurement scale, each category average measures must advance monotonically for each set of observations and the outfit mean square (MnSq) values for each step category should also be less than 2.0 (106).
Person response validity and internal scale validity were investigated in the dataset using the person and item goodness-of-fit statistics and infit MnSq values >1.4 logits. Then the associated standardized $z \geqslant 2.0$ values (107) was a criterion for not demonstrating the acceptable goodness of fit. Usually, 5% is acceptable if the persons and items by chance do not show the acceptable goodness of fit (108). Further, the scale validity was tested using a principal component analysis (PCA) of the residuals (109) and the set criteria for variance explained in each of the domain categories were set to 60%.

The stability of the item response patterns in the SIS 3.0 Uganda version considering gender, age, civil status, level of education, side of the affected body, and previous work status were also assessed. To check for threats to validity, where an item can function

differently for certain groups, differential item function (DIF) analyses were performed using Mantel–Haenszel for the polytomous test in the WINSTEPS program at a level of significance ($p < 0.01$) (109). Then a criterion for the person-separation reliability index was set to ≥ 1.5 to measure the domain that would clinically separate the sample into two or more different strata, for instance, lower and higher levels of perceived impact of stroke (110). An equivalent measure of Cronbach's alpha using the WINSTEPS program is computed which indicates the reliability of the scale. A criterion was set to exceed 0.80 of the reliability coefficient.

Analysis of the interviews in Study III

Study III followed the guidelines provided by Charmaz (111). All the interviews were transcribed verbatim and carefully read line by line, after which analysis followed the guideline for the constant comparative method. In this method, concepts and incidences are analysed simultaneously. Continuous memo writing was carried out throughout the analysis that generated categories. When performing the initial coding, questions, memos of reflections, and ideas that emerged during the analysis were written as they occurred. Concepts and incidences were analysed in order to gain knowledge of the experiences of how persons with stroke used mobile phones in their everyday life after stroke. During the period of analysis, categories and memos were discussed amongst the authors in order to improve resonance (111).

RESULTS

CULTURAL ADAPTATION AND PSYCHOMETRIC EVALUATION OF STROKE IMPACT SCALE 3.0 UGANDA VERSION

In **Study I,** cultural adaptation of four of the domains – Strength, Memory and Thinking Emotion and Communication were evaluated as having relevant word expressions in the Ugandan context. Some items in the domains Participation, Mobility, Hand function and ADL/IADL needed to be altered in order to have relevant meanings. Seventeen percent (10 out of 59) items needed to be culturally adapted.

The Rasch analysis of the rating scale properties of SIS 3.0 Uganda version indicated good rating scale functioning overall except Emotion domain where only 51.5% of its total variance in the sample was explained by the first dimension demonstrating an outfit MnSq value exceeding 2.0. The analysis of internal scale validity revealed that all items in the Strength, Memory and Thinking domains demonstrated acceptable goodness-of-fit but the other six domains included at least one item not showing acceptable goodness-of-fit. In total,

eight out of 59 items showed misfit to the Rasch model (13.6%). When the items demonstrating misfit were deleted from each domain the results of the Principal Component Analysis (PCA) were supporting unidimensionality for all domains except for the Emotion domain. For the Emotion domain only 51.5% of the total variance with in the sample was explained by the first dimension, indicating that unidimensionality for this domain can be questioned. For the person response validity, more than 5% persons were demonstrating misfit in the domains Participation and Emotion while Communication, Mobility, and Hand function domains had the lowest proportions of person misfit. There were also one item in the ADL/IADL domain and one item in the Participation domain that demonstrated significant differential item functioning (DIF); "dress the top part of the body" demonstrating a DIF in relation to body side affected and "limited in social activities" demonstrated DIF in relation to marital status. There were no items demonstrating DIF between the different SIS 3.0 Uganda language versions across the domains.

The person-separation index of the domains of Strength, ADL/IADL, Mobility, Hand function, and Participation were all above 1.5 indicating that they could separate the sample into two or more groups. The domain Emotion had a person separation index of 1.43; meaning that it was not able to separate the sample into more than one group. The reliability coefficient in the Emotion domain was below the set criterion of 0.80 (0.75) but in all other domains the coefficient was equal or higher than 0.90.

In conclusion, even though findings were mixed, the psychometric evaluation showed that SIS 3.0 Uganda version has overall acceptable validity that could measure the perceived impact of stroke in Uganda. However, more studies with larger samples are required for further adaptation and improvement of the SIS in this context.

CLINICAL CHARACTERISTICS AND PERCEIVED IMPACT OF STROKE IN UGANDA

In Study II, the clinical characteristics were described in an acute/subacute sample (time since stroke onset 2 days to 3 weeks) and a chronic sample (3 months-3 years since onset). The mean age of the acute/subacute sample (n=58) was 49 years; 81% had moderate or severe stroke and 88% were dependent in ADL. The mean age of the chronic sample (n=62) was 53 years; 58% had mild stroke and 27% were dependent in ADL.

The SIS 3.0 Uganda version was used to evaluate the perceived impact of stroke in the chronic sample in Study II. The Strength, Participation and Hand function were the most

impacted domains with mean scores of 44.7, 36.5 and 28.8 respectively. The Hand function had the lowest median domain score of 10, indicating problems in everyday occupations. The mean scores in Communication and Memory and Thinking were higher, 84.4 and 85.1 respectively, indicating fewer problems. The self-reported Stroke recovery ranged from 40 to 90, with a median of 60.

MOBILE PHONE AS AN ENABLER OF PARTICIPATION IN EVERYDAY LIFE

In Study III, the experience and meaning of using mobile phones in everyday life after stroke was explored and described. The findings supported the mobile phone as a valuable device that could enable participation in occupations in everyday life after stroke for someone with stroke and their family members. The mobile phone was described as a lifeline that extended the body, enabled connection, belonging and agency to act in a complex everyday life situation. In the cultural context of the study, belonging is an important facet of quality of life, and the mobile phone seemed to facilitate connections with friends and family members. The mobile phone was referred to as a *"close friend"*, and without it *''life would be difficult''*, meaning that mobile phones played a crucial role in people's everyday lives.

Mobile phones enabled persons with stroke to structure their daily routines and ADLs and facilitated their economic well-being, since they were perceived by other family members as being able persons. Reintegration into community living of persons with stroke was facilitated by the mobile phone, as it gave them confidence and reassurance that they could be reasonably independent. Mobile phones promoted agency to take part in everyday occupations as in leisure and social activities and feelings of control for persons with stroke and their family members in their everyday life.

THE OUTCOMES OF MOBILE PHONES IN REHABILITATION AFTER STROKE

In Study IV, the feasibility of a mobile phone supported family-centred ADL-intervention F@ce^{TM} was evaluated. The feasibility of the methodology of conducting this new intervention after stroke in Uganda was found to be viable, although problems of receiving and sending text messages were experienced by the majority of the participants. The consent rate was good, as well as the interest in receiving the intervention.

The perceived impact of stroke was assessed in the intervention group (n=13) and control group (n=15) by using SIS 3.0 Uganda version at baseline and at eight weeks later. The domain Hand function and Participation were the most impacted domains; with mean scores in IG 5.4 and 12.7 respectively, and for CG 10.7 and 19.8 respectively. The domain scores in

Memory and Thinking and Communication were the least impacted, with mean scores of IG 69.5 and 71.2 respectively, and CG 81.4 and 88.6 respectively.

The perceived participation was assessed by COPM performance and satisfaction components and Self-efficacy. The results of the COPM performance component showed a significant difference between the IG and the CG in changes overtime between the baseline and the follow-up (p=0.050). The COPM satisfaction component did not show significant difference between the IG and the CG in changes overtime between the baseline and the follow-up (p=0.12). Ten out of 13 participants in the IG showed a two-point clinically significant improvement in performance compared to seven out of 15 in the CG. The satisfaction component of the COPM showed that nine participants in the IG that had a two-point clinically significant improvement compared to five participants in the CG. The Figure 4 shows the difference in COPM performance and satisfaction components between the IG and CG at baseline and after 8 weeks follow-up.

The Self-efficacy scale as a measure of perceived confidence in performing everyday occupations showed a significant difference between the IG and the CG in changes overtime between the baseline and the follow-up (P=0.038) in favour of IG. The Figure 5 shows the differences of confidence in performance in targeted occupations between the IG and CG at baseline and after 8 weeks follow-up

The OGQ and BI were used as secondary outcome measures in Study IV. Neither OGQ nor BI showed significant differences in outcomes between the IG and CG (p= 0.39) and (p=0.06) overtime, but the participants showed consistent improvements in gaps and ADL performance respectively after eight weeks of intervention.

Figure 4 showing COPM Performance component and Satisfaction component in the two groups

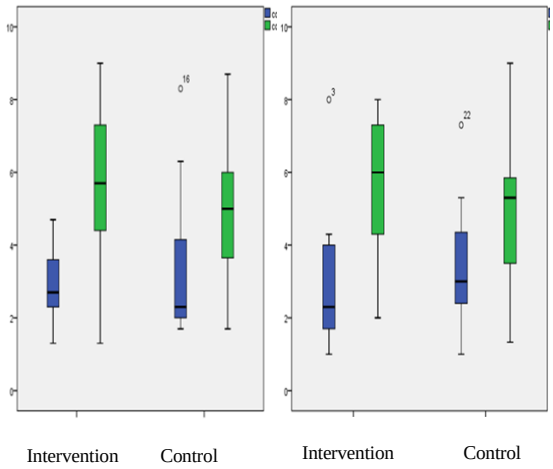
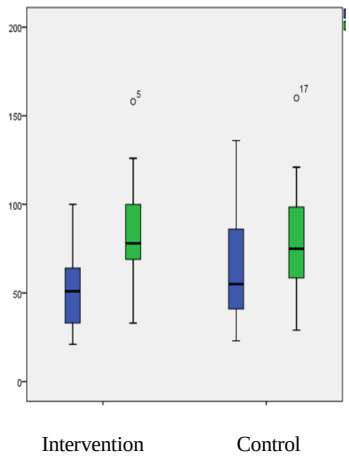


Figure 5 showing the difference in Self efficacy between the IG and CG



GENERAL DISCUSSION

There is limited knowledge on how post-stroke rehabilitation can be organized in Uganda, and there are limited resources for rehabilitation. Public transport is not reliable; the homes of people with stroke are not easily accessible, and rehabilitation specialists are scarce. The studies in this thesis are the first to be conducted of the impact of stroke in the Ugandan context.

In this section, the results of the empirical studies will be discussed in relation to the conceptual framework based in occupational therapy. The general discussion will cover the results regarding instrument adaptation and validation, the clinical characteristics of stroke, the perceived impact of stroke and perceived participation in everyday life, the perceived meaning and experience of using mobile phones in everyday life after stroke and how participation in everyday life can be enhanced after stroke by the use of the mobile phone-supported family-centred intervention (F@ce TM). The discussion will cover barriers to rehabilitation as well as a justification for developing F@ce TM and what implications the findings of this thesis may have for future research and the improvement of rehabilitation services in Uganda.

This section will be discussed under the following sub headings: participation in daily occupations in the cultural context of Uganda; challenges in everyday life and rehabilitation needs after stroke; the mobile phone as a tool to facilitate rehabilitation; family-centeredness as a therapeutic component for rehabilitation interventions; evaluation of complex interventions, the intervention process; the future horizon of rehabilitation in Uganda and future studies for developing rehabilitation after stroke in Uganda, as well as methodological considerations.

PARTICIPATION IN DAILY OCCUPATIONS IN THE UGANDAN CULTURAL CONTEXT

This thesis has generated new knowledge regarding participation in everyday life in the context of Uganda. In order to describe everyday life as perceived by people with stroke, there was a need to find an instrument to use for the different studies but also to be used in the health care and rehabilitation. The SIS 3.0 instrument is commonly used in stroke rehabilitation and has been culturally adapted into different international contexts. The results in Study I showed the cultural relevance of the adapted items in the domains of Participation, Mobility, Hand function, and ADL/IADL that required revision. When viewing these items, e.g. activities, from a contextual viewpoint, the expressions were changed to relevant contextual equivalent meanings. By viewing these items e.g. activities, the expressions were changed to relevant contextual equivalent meanings (experiential, conceptual, idiomatic and semantic (112). It complies with another study from Nigeria where they also needed to change expressions used for the objects used in everyday life/for more culturally acceptable linguistic equivalents similar to the concepts and meaning to the

original objects (113). Overall, 10 of 59 (17%) items in the eight domains were culturally adapted from the original SIS 3.0 into a SIS 3.0 Uganda version that was used in Studies II and IV in this thesis.

In the context of Uganda, the daily occupations are carried out differently compared to how they are carried out in high- and middle-income countries where everyday technology, machines such as vacuum cleaners, washing machines and other household equipment, are used to facilitate occupations. In Uganda, however, people use sweepers made out of sticks to sweep rough compounds, and in most of the households, people use their hands to wash their clothes, wash the dishes, and use containers to carry water from the well, which gives support to the importance of cultural adaptation of the assessment instrument to fit the context (101). Furthermore, Study IV showed that people with stroke set targets for their rehabilitation activities that were relevant to them in the cultural context in which they were performing. The majority of the targets in daily activities chosen by those with stroke were categorised and related to productivity and self-care, and were formulated based on a traditional way of performing them guided by values and everyday experiences such as sorting beans or rice, sweeping, gardening, peeling bananas, reciting the Rosary during prayers, singing, dressing, washing clothes and bathing. Few targets were leisure, which could be an indication that that most people in this context carry out activities that fulfil primary physiological needs rather than the needs of self-esteem and self-actualisation (27). The target activities were performed with regularity to improve participation in their everyday lives, and the findings suggest that the participants became engaged and followed the intervention programme that they participated in, developing targets to improve their participation in everyday life. This is in accordance with theories and models within occupational therapy (5, 6).

According to the Model of Human Occupation (MOHO), participating in occupations and routines is the choice of the individual and depends on diverse occupational settings (6). In line with MOHO the occupational therapists involved in Study IV enabled the individuals to participate in meaningful activities of their daily life through collaboration. The point of departure for the intervention was that people with stroke were motivated to engage in activities that were relevant to them, thereby enabling agency, a feeling that one was responsible for their actions and outcomes. According to the MOHO, participation is influenced by one's motivation, habits, performance capacity and context. The findings from Study IV regarding the choice of activities and how the participants implemented the

intervention is in accordance with MOHO and confirms that occupations occur in a complex and multi-layered environment.

CHALLENGES IN EVERYDAY LIFE AND REHABILITATION NEEDS AFTER STROKE

According to WHO (1) "70% of strokes and 87% of both stroke-related deaths and disability-adjusted life years occur in low- and middle-income countries". Relatively young people are affected by stroke, which was also found of this thesis. The reasons for stroke at younger ages, higher rates of haemorrhagic subtypes and higher case fatality, are unknown (3). The majority of the people with stroke in the acute/sub-acute sample (Study II) had moderate or severe neurological impairment, indicating that this group was more likely to seek medical attention and be admitted to Mulago Hospital in Kampala.

The findings from Study II showed that Strength, Hand function and Participation were the most affected domains; this could have been that, since most daily occupations in the context of Uganda, are performed manually and require more physical strength, hand impairment was interpreted and perceived as having a significant impact on daily life for people with stroke. Hand function has been proven to account for 32% of the single most important indicators of global recovery after stroke among people <65 years, one year after stroke (114).

In Studies II and IV, the greatest perceived impact of stroke was shown in the domains of Strength, Participation and Hand function compared to previous studies (115, 35). That might be due to the dependency of a good hand function as the main facilitator of participating and making everyday life and work in Uganda, as shown in a study from Rwanda (116). It seems as if most daily occupations in low-income countries require more motor function/strength for their accomplishment than in high-income countries. However, the results should be interpreted with caution, since the participants in the chronic sample in Study II were mainly recruited at physiotherapy units which might have prioritized motor dysfunction.

Furthermore, the results from Study II have shown that perceived impact of stroke is high in Africa compared to high-income countries. Stroke was more severe in the acute sample than in stroke units in high-income contexts, which has been reported by (117). In addition, most available knowledge concerning the effects of rehabilitation interventions are based on research carried out in high-income countries, and there are no current interventions that have proved effective across cultures. Rehabilitation intervention after stroke is a complex process

comprising various interacting components. Therefore, there is a need of more knowledge on the impact of stroke in order to develop guidelines for stroke care in Uganda, including rehabilitation interventions that are feasible in the Ugandan health care context both in rural and urban areas.

Studies II, III and IV described the impact of stroke on communities in Uganda and that stroke seems to affect adults in their most productive age, affect poor communities, pushing individuals and households further into poverty, presenting long-term psychosocial challenges. The findings give support to the current demands for rehabilitation services, which are partly due to inadequate numbers of rehabilitation professionals such as OTs and physiotherapists.

Rehabilitation of people with stroke in the Ugandan context falls under Community Based Rehabilitation (CBR). CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities and social inclusion of all people with disability (118). CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (118). Using the principles of CBR to work with the community might be one way to improve the rehabilitation services in Uganda. In Study IV it proved effective to work in peoples' home environments.

Research has shown that the experience of having a stroke is associated with limited participation in ADL activities (15) and those activities such as communication, interaction and socializing with friends could improve participation. In the context of high- and middle-income countries, Lawler et al. showed that the efficacy of rehabilitation interventions is moulded by the quality of the social connectedness among all of the social actors in rehabilitation (119). This supports the idea of implementing the family-centred approach that is adopted in this thesis so as to reflect the collaborative relationship aimed at promoting participation in everyday life after stroke.

MOBILE PHONES AS A TOOL TO FACILITATE REHABILITATION

Research has shown that mobile phones have become valuable tools in health care interventions, since they can produce detailed and personalised data that can be used to strengthen health in the areas of prevention, diagnostics, treatment or rehabilitation and among persons who are socially excluded in society (120). The findings from Studies III and IV have generated new knowledge about how mobile phones could be used to facilitate

rehabilitation in low-income countries. The result from Study IV gave support to the mobile phone supported family-centred intervention that might resolve the problems of accessibility and affordability of rehabilitation by people/families living with the consequences of stroke.

The results from Study III indicated that mobile phones could be used as a tool to enable participation and agency to participate in everyday life after stroke, since the participants seemed to be empowered by the mobile phones to participate in everyday life. This is in line with Masterson Creber et al. (121), who showed that empowering a person with stroke using a mobile phone to manage their disability may nurture both purposeful participation in goal attainment and self-management of the disability (122). Previous studies have shown that mobile phones can provide support to people with low incomes who may not have the opportunity to access face-to -face therapists due to rehabilitation costs or insufficient incomes (123, 124).

The findings in Study III indicated that the mobile phone promoted communication, which was expressed as vital in the interactions between people, and hence aided social participation of both people with stroke and their family members. The mobile phone was found to be a lifeline and an extension of the body enabling connection, belonging and agency to act in a complex everyday life situation. It has previously been said that people after stroke incorporate familiar objects and activities in their everyday lives (125). When objects are incorporated as an extension of the body (8), as, for example, mobile phones in the context of Uganda, they are taken for granted in everyday life. The findings in Study III indicated that the mobile phones were incorporated and taken for granted in everyday life among the people with stroke, which give support to the possibilities of using mobile phones in the rehabilitation after stroke in Uganda. Therefore, mobile usage was associated with strong incentives that could facilitate the recovery process. Due to the perceived attractiveness of using mobile phones in everyday life after stroke, the participants seemed to be inspired to use different functions e.g. the calendar to organise their time, the camera to take pictures to remember important things, the reminders from others via text messages, which are also described in several studies from the high income countries (123). The mobile phone has been said to be easy to incorporate into everyday habits and routines both at home and outside the home (123).

Stroke often leads to limitations in interaction, and the mobile phone seemed to have re-connected people with stroke back to the social world. This is also described in a study

from Sweden (126), where family and friends kept in touch more frequently through phone calls and text messages after the stroke. The possibility of maintaining a constant connection with friends and relatives was facilitated by mobile phones, which in turn improved their sense of belonging (123). According to what Hammel stated "belonging is positively correlated with human well-being, is valued by the majority of the world's people, and informs the meanings attributed to and derived from the occupations of culturally diverse people. If occupational therapy is to address meaningful occupations, attention should be paid to occupations concerned with belonging, connecting, and contributing to others". Previous research has identified the importance of belonging to person's well-being and has also provided evidence-based support for an occupation as a medium for expressing and achieving a sense of belonging and connectedness (125). Activities related to people's interaction and connection with friends and relatives could, therefore, be useful in rehabilitation interventions in order to enhance the sense of belonging (127).

Research has shown that mobile phone use within health-care settings promotes participation by facilitating self-initiated behaviours, self-management and equality in communication, since it endorses agency and doing in everyday life (71). For example, the mobile phone seems to have improved motivation and engagement when people with stroke first communicate using a mobile after stroke and take pictures to remind them of past events. In Study III, the mobile phones improved motivation for engagement in life activities of the people with stroke and enabled agency (i.e. a feeling that one was responsible for one's own actions and outcomes). The people with stroke discovered their own abilities and limitations through communication, and the immediate feedback they received gave them hope and courage to engage in daily living activities. They used their mobile phone as a tool to influence their actions in everyday life and engage in family role expectations.

In Study IV, the mobile phones sent text message reminders as a part of the intervention to the participants to perform the target activities. The feedback through phone calls the OTs made to the participants with stroke were useful and acted as facilitators to engagement in the target activities. The monitoring of the occupational performance with the SMS seemed to increase participation in everyday occupations after stroke. The phone calls increased the clients' desires to participate in their own health management and gave them the feeling that they were not neglected but were being taken good care of. These findings are supported by previous research (128, 129). The findings in Study IV also seemed to create the possibility

of dialogue between therapists and people with stroke or family members about appropriate therapeutic activities to be performed outside the rehabilitation unit. The feedback seemed to be an important facilitator of the process of change, which is supported by Lopez and colleagues (130) who studied the daily phone reminders in the form of test messages, which may have promoted the significant positive outcome in self-efficacy in the intervention group. Previous studies have shown that text messaging via mobile phones can overcome barriers in rehabilitation, and reminder messages are widely accepted and effective where the population is literate (120). Earlier research, summarised in a literature review (131), has shown that mobile phones can facilitate occupational performance, health and wellness, adaptation, prevention, and quality of life (123,131). The findings in this thesis can serve as a point of departure for the integration of mobile phones and, based on the results from Study IV, the intervention can be feasible in the context of Uganda.

FAMILY-CENTREDNESS AS A THERAPEUTIC COMPONENT FOR REHABILITATION INTERVENTIONS.

The family-centred approach used in this thesis was a preferred approach based on contextual tradition (6) and was adopted in Study III during data collection and Study IV during the intervention process. The family members were involved in the care and supported the client during the rehabilitation intervention.

Carl Rogers (45) showed that, in order to understand and comprehend human nature, it is important to consider people's perceptions and feelings and how they experience their phenomenological world. Therefore, in order to understand the phenomenon of everyday life of the people with stroke in Uganda, it was important to involve family members in the intervention processes. Family-centeredness emanated from observed patterns of behaviour in a caring relationship between the client and family members, and it was an approach to practice generated by therapists in Uganda to guide their clinical work. Previous studies have shown that psychosocial and emotional support, provided by both rehabilitation teams and those from the environment, to patients with long-term illness promoted participation (132) in occupations after stroke. The family-targeted activities involving the family helped to define family relationships and their well-being, which is in line with what Lawlor and Mattingly proposed about engaging the family (119). It seemed important to involve the occupational therapist in the families' everyday life and situation after stroke. This was needed because the members of the family could not provide the intervention strategies necessary for the intervention but were able to choose activities they needed and that required attention, and similar findings have also been reported by Lawlor and Mattingly (119). However, studies conducted in Nigeria and India have shown that social support which is deeply rooted in

culture of strong kinship ties, communal living, did not influence participation positively, and consequently did not enhance good quality of life after stroke (133, 134).
In the Ugandan culture, participation in social life promoted belonging and it is the responsibility of family members to provide that interaction. Different environmental factors such as physical and social environment may significantly influence participation among people with stroke. Social support has been shown to positively influence participation (133), and in Study IV the intervention goals set by the family members together with the client were achieved by their combined effort.

The family-centred perspective in the intervention was important because stroke does not only affect the patient, but also the whole family and other extended family members in Uganda. Therefore, coping strategies, emotional reactions, social and community support and participation become issues not just for the person affected by the stroke, but the whole family. In order to understand the person with stroke, it was important to involve the whole family since Ugandan society is structured based on the extended family. The approach of family-centeredness in Uganda seem to be the appropriate way to reach people with stroke and to deliver relevant intervention to the community.

EVALUATION OF COMPLEX INTERVENTIONS – THE INTERVENTION PROCESS

This thesis tried as closely as possible to follow the guidelines of MRC (135) since the goal was to develop a complex intervention that could be used within rehabilitation after stroke. Occupational therapy interventions are complex and can be characterized by; "the number of interacting components; the number and difficulty of behaviours required by those delivering or receiving the intervention; the number of groups or organizational levels targeted by the intervention; the number and variability of outcomes; and the degree of flexibility or if tailoring of the intervention permitted". However, Craig et al. (61), recommends that the outcomes based on the perspectives of the user (individual, family or community) are crucial in the evaluation of complex intervention. Therefore, the analyses may be more or less valuable to different types of user, since some users may want to know about the process and others the outcome and some others may want to know about both the outcomes and the process (136).

Study IV was a feasibility trial of a mobile phone supported family-centre ADL intervention, and was done as a prototype of the CADL model that was previously

implemented in Sweden (58). Before starting the trial, a logic model was drawn up detailing the process and the content of the model (62). The model contained training workshops, regular meetings, client assessments and support from researchers, conducting follow-up phone calls, SMS, writing logbooks. Findings from the feasibility study (Study IV) showed that the content of the intervention was delivered as planned. However, the findings also indicated that context played a major role when implementing interventions, which is in line with previous research (61, 62, 136, 137).

The most important contextual mediator in this project seemed to be the supportive working culture of the family members and this was made to conform with the MRC guidelines of tailoring the intervention to the local circumstances (135). However, there were contextual barriers that might have affected the process and the outcomes (136, 137) that were related to technical problems as well as the people with stroke and their family members' lack of adherence to the intervention provided.

Findings from this thesis are in agreement with earlier research (123, 124) showing the potential benefits of using a mobile phone as an appropriate alternative to traditional rehabilitation services in order provide accessible services to the client who is at some distance from health units. This approach allows services to occur where the client lives, if that is needed or desired. This is in line with several other researchers (123, 124) showing that, through the context, the level of adaptation is challenging the intervention and seems to have had a great deal of integrity defined by outcomes rather than technical issues (138). The mobile phones have removed barriers by reducing travel and have provided access to rehabilitation.

The problem-solving strategy used in the intervention has been described earlier (139, 140) and it enhances self-monitoring of performance demands, self-observation and self-evaluation. The rehabilitation intervention used in this thesis when applying the problem-solving strategy "target-plan-perform-prove" seems to promote self-discovery and adaptation in performing activities. Complex interventions argue that "the greater the difficulty in defining precisely what exactly are the 'active ingredients' of an intervention and how they relate to each other, the greater the likelihood that you are dealing with a complex intervention" (137).

THE FUTURE HORIZON OF REHABILITATION IN UGANDA

This thesis within the field of occupational therapy was the first step in the long journey of developing rehabilitation interventions for stroke survivors in Uganda. The empirical findings from this thesis contribute new knowledge that can be utilized in occupational therapy as well as in stroke rehabilitation in Uganda. Occupational therapy in Uganda lacks a number of standardised instruments that can be used in practice. Thus, the instruments that were adapted and used in this thesis can be used in clinical practice. The occupational therapist in Uganda uses traditional bio-medical perspectives of looking at aspects of a dysfunctional body. This thesis provides the theoretical perspectives in both occupational therapy and occupational science that is described in contemporary literature. The findings focus attention on the provision of culturally sensitive rehabilitation interventions that are based on the needs of the people with stroke and are therefore relevant. The findings in this thesis are meant to benefit occupational therapists working in Uganda and in other sub-Saharan African countries. However, the findings can be utilised even in high-income countries for cross-cultural comparisons of research data. The following are the most important clinical implications.

- The adapted, translated and validated instrument SIS 3.0 Uganda version can be used for assessing the perceived impact of stroke among stroke survivors in Uganda. *(Study I)*

- *Study II* has contributed to an understanding of the demographics and clinical characteristics of people with stroke, indicating that a younger population compared to that in high-income countries is affected by stroke, and that the people who are admitted to hospital have severe stroke. Furthermore, the perceived impact of stroke among the stroke population in Uganda is higher than was reported from previous studies, indicating a need to assess the perceived impact of stroke and increase the provision of rehabilitation interventions for this younger group of people facing stroke in mid-life.

- The meaning of using mobile phones in everyday life after stroke indicated that mobile phones is a lifeline and an accessible and affordable technology used in daily life of people with stroke and family members and could connect them to the services needed for rehabilitation. *(Study III)*

- The intervention model "mobile phone supported family-centred ADL intervention (F@ce^{TM})" is feasible in the Ugandan context and increases participation in occupations of people with stroke in everyday life after stroke. *(Study III)*

- To use a family-centred approach was an important facilitator in the recovery process after stroke. Occupational therapists and other rehabilitation professionals should prioritise involving family members in order to increase participation which will support sustainability of the rehabilitation intervention. (*Studies III and IV)*

- Findings from *Study IV* support the clinical value of COPM in setting goals as well as monitoring and evaluating clients' activity performance and satisfaction in the context of Uganda.

- The mobile phone supported family-centred interventions used in this thesis seemed to improve self-efficacy in everyday life. *(Study IV)*

METHODOLOGICAL CONSIDERATIONS

The four studies in this thesis contribute new knowledge on cultural adaptation of the SIS 3.0 and its use in the Ugandan context as well as the feasibility of using the mobile-phone as a tool in rehabilitation after stroke. The four studies employed different study designs and samples as well as analyses and instruments. The thesis used both quantitative and qualitative approaches that offered different perspectives complementing each other. The samples and designs and methods used need, however, to be reflected upon, as well as the generalisability of the results which will be discussed in the following.

Design and sample size

Studies I–III had a cross-sectional design due to the specific research questions, but this design was also used because it was found to be feasible. The original plan in Study II was to use a longitudinal design, but that was changed due to difficulties in reaching the participants for a follow-up. In Study IV, a prospective pre-post design was used with two measuring points, which provided information on the feasibility of the design and some aspects of change during the intervention could be identified.

Samples

Due to the lack of organized stroke services for the care and rehabilitation of people with stroke, identifying the participants was a long and difficult process in all the studies in this thesis. Participants who took part in Study I were also taking part in the acute/subacute sample in Study II. In the same vein, some participants in Study I also took part in Study III. These participants were all recruited in the acute setting at Mulago Hospital. The chronic sample in Study II was a new group of participants recruited from different rehabilitation

units. The participants for Study IV were also distinct from the other samples and recruited for that specific study from various hospital/rehabilitation units.

In all four studies, it was a strength that the demographic characteristics in the samples were similar to those in previous studies of people with stroke in other Sub-Saharan countries (141, 142, 143). However, the samples in all the four studies were small because of the difficulties related to sites for recruitment, and the size of the sample thus limits the possibility to generalise the findings.

In Study I, a small-scale study, a sample size of approximately n = 100 was suggested in order to provide a relatively stable pattern of responses and detection of misfitting items (144) with Rasch model analysis; however, due to difficulties recruiting, only 95 participants were recruited. Further research of SIS 3.0 for use in Uganda is warranted including a larger number of participants and also people from rural areas.

In Study II, a similar scenario of identifying an adequate sample altered the original design to conduct a prospective longitudinal design. The two separate samples were identified in a cross-sectional design instead of a prospective longitudinal design, which could have provided relevant information on the people with stroke, as the process of recovery and returning to their everyday lives after stroke onset, their perceptions of impact of stroke over time, and their need of rehabilitation to regain functioning. Originally, the design of the study was to recruit everyone with stroke on the neurology ward at baseline assessment and then come back to them for follow-up at three months after stroke onset. This was not possible, since majority of people with stroke that were found on the neurology ward at Mulago Hospital had severe stroke and it was difficult to trace them after discharge. The attrition rate was high due to the fact that many were deceased; others went to their up-country homes and could not be contacted. Owing to the high attrition rate, the design was changed to a cross-sectional study involving two separate samples. In order to collect information on the perceived impact of stroke from people with less severe stroke who were no longer in the acute phase after stroke, there was a need to involve participants who received rehabilitation.

Methods used

In Study III, constant comparative grounded theory (GT) study was used to focus on the individual experiences and opinions of the participants. A GT approach was chosen for this study because it is considered to be suitable if a new area is explored or if a known area with

another perspective is explored (145, 146). Longitudinal data collection from stroke onset and during the first year would have been preferable (147, 148) in order to better understand how mobile phones were used during the process from stroke onset back to community living. Longitudinal data collection assesses multiple disease aspects such as changes of outcome(s) over time in relation to associated risk factors and group patterns over time. Nevertheless, saturation was obtained, which is an important principle when using a GT approach.

The interviews in Study III were mainly conducted in the home environment, and various people e.g. family members, neighbours etc. were coming and going and activities performed within the home interfered with the interviews, which could have influenced their trustworthiness. This was, however, allowed in this context where a patient cannot be isolated from their families. One of the inclusion criteria in Study III was that people with stroke should use mobile phones before and after stroke. However, those who had a longer post-stroke duration and those who had mild to moderate impairments used the mobile phones in their daily activities more and articulated better their experiences when compared with those who only had a stroke a few weeks earlier.

In Study IV, the sample was small and, being a pilot feasibility study, it was not powered to draw conclusions regarding the effects of the F@ce™ intervention. Nevertheless, F@ce™ intervention could have had beneficial effects because the intervention group, though older and with severe stroke, had better outcomes. A limitation was that the majority of the recruited participants in both groups kept on receiving physiotherapy during the study, but it is likely it would be similar in the two groups. The therapy received could have had an effect on the outcomes. Other limitations of Study IV were a lack of: i) allocation concealment, ii) randomisation of participants throughout the study, and iii) blinding of the data collector. In future studies of F@ce™, these issues mentioned above should be addressed.

Instruments

For this thesis, it was difficult to find instruments valid for the context in order to evaluate capturing the changes in occupational performance in and the impact of stroke. The SIS measurement represents the patient perspective and is therefore referred to as a patient reported outcome measure but needed a cultural adaptation. The SIS Uganda version in Study II and IV worked very well for the researcher to use and is also recommended to be used in clinical practice.

In Studies II and IV commonly used and well-established assessment instruments such as the BI and the SSS gave greater credibility to the results, which could thereby be compared to other research findings. The BI is the most used scale in the area of stroke and measures dependence in personal ADL (149). The SSS measure represents the views of health care personnel with regard to stroke severity. In Study IV, three more instruments, COPM, OGQ and self-efficacy, were added to the above list. The COPM was to my knowledge used for the first time in research conducted in the Ugandan context to capture a client's self-perception of performance in everyday living over time. COPM was a good instrument to facilitate the setting of targets (goals) and the monitoring and evaluation of performance. COPM is recommended to be used in clinical practice in Uganda as well as in research.

OGQ is a self-report inventory which has also earlier been culturally adapted (reported elsewhere) (104) that can facilitate gathering information about and understanding of the client's situation with respect to perceived participation in daily occupations, also in Uganda since the items are validated for this context. Furthermore, a project-specific self-efficacy measure was used that was adapted for people with stroke but was not evaluated before being used in Study IV. This could be seen as a limitation in the results, although according to (99) scales of perceived self-efficacy must be tailored to the area of functioning, which was done (99).

In both Studies II and IV, all the data were collected in face-to-face interviews, and this was a strength, as written self-reports were not feasible for all participants due to language and literacy complications. Data collection in Studies I, III, VI and in the chronic sample of Study II was made in the participants' homes, which allowed for validation of the participants' reports. A substantial amount of time was required to complete the assessment in Study IV, which made the responded exhausted of the participants, which indicates that the number of instruments need to be considered in the future studies. These experiences might have a measurable effect on the outcomes. Overall, having tested different instruments in Uganda gives a basis and alternative for different use in both clinical and research for the future within the area of health care and rehabilitation.

Generalizability of findings from the studies

Studies I, II and IV were quantitative studies, and the sample sizes were small and all samples were drawn from the multi-cultural capital city of Kampala, and thus could reflect to a greater extent the characteristics of the urban population. Therefore, findings can still

be viewed as providing pilot evidence. In Study I, the sample was small, and a larger and more representative sample is necessary for any type of definitive statistical analyses in order to draw definite conclusions regarding the validity of the SIS 3.0 Uganda among the population with stroke in Uganda. The Rasch model provided only pilot validity evidence of SIS 3.0 Uganda in the Ugandan context (150). Hence, caution should be observed when applying the results to a broader population of individuals with stroke in Uganda and other Sub-Saharan African countries, considering that the small sample was from urban and peri-urban populations

The aim of qualitative research is not to generalise findings, but to describe the experiences and meaning in order to gain a deeper understanding of what is being studied (151). In Study III, the experiences of using mobile phones after a stroke were explored. General categories were found, and there were some categories in agreement with other qualitative studies (126), but some new characteristics were also discovered. The knowledge from Study III served as a basis for in F@ce, and the long-term goal was to develop and implement a model for mobile phone supported family-centred rehabilitation intervention, with applications for sub-groups, using purposeful sampling and a varied context. This implies that findings cannot be generalised to other contexts that do not have similar environmental, cultural and economic characteristics.

In Study IV, the RCT design was tested in a feasibility study with a small sample, and conclusions regarding the effects of the F@ce^{TM} intervention are not generalisable. In a future RCT study, there is a need for improvements in recruitment, allocation concealment, randomisation and blinding of data collectors. In general, the results support the need for conducting further research in this area and can be applied to environments that have similar cultural contexts but should also include participants from rural settings.

ETHICAL CONSIDERATIONS

All ethical permits for the studies within this thesis were secured from the Uganda National Council for Science and Technology (UNCST) No. HS 703. The ethical implications of the studies within this thesis were mainly related to the interviews and procedures participants included in the research were exposed to. Participants were first informed about the purpose of the study and nature of their participation, and thereafter each of them signed a consent form. The data collected in this thesis (the instruments) was based on the participants' perceptions of functioning and the perceived impact of stroke. One ethical dilemma could be that the questionnaires could have aroused feelings of anxiety and sadness and the questions

could have hurt their integrity. My experience is, however, that most participants like to share their experiences from their everyday situation with experienced therapists involved in research. Furthermore, all participants were informed that they could refuse to participate or withdraw from the study at any time.

There was an issue of excluding those people with stroke who had major cognitive impairments, communication problems, those who lived far from Kampala City and those who were aged less than 18 years and above 75 years. These individuals might possibly have wanted to participate in the study. The decision concerning inclusion criteria was meant to include those participants who had characteristics of stroke without being compromised by other confounding factors.

In Study IV, the ethics of not supplying rehabilitation services to the control group need to be considered. One method could be to apply a waiting list design. Furthermore, aspects of using the tablet to capture personal health-related data could raise concerns about health data security and confidentiality, although codes were assigned to participants and telephone numbers. There are possible ethical dilemmas in conducting an RCT study where participants who belong to the control group do not receive the intervention. However, all participants in the IG and CG received information about stroke and the need for ADL independence, set targets according to COPM, were given hand exercising balls and had their blood pressure taken.

FUTURE STUDIES

The findings in this thesis reveal the need for a number of future studies. At first, there is a need to explore the psychometric properties of SIS 3.0 Uganda version using larger and more heterogeneous samples in which a more rural-based stroke population should be included. Furthermore, item hierarchies of SIS 3.0 domains across contexts and cultures need to be examined in order to make valid comparisons between international samples with stroke. Additionally, more explorative work should be pursued involving people with stroke and their families by using relevant culturally adapted assessments in their everyday life situation. There is a need for more knowledge on the impact of stroke in order to develop guidelines for stroke care in Uganda including rehabilitation interventions that are feasible in the Ugandan health care context both in rural and urban areas. A further study is required that will involve the perspectives of not only the people with stroke and their family members, but also of policy-makers and rehabilitation professionals to increase the

understanding of applying mobile phone calls, SMS or reminders to increase accessibility and effectiveness of mobile phone supported rehabilitation interventions.

As a continuation of Study IV, a full-scale randomised controlled trial examining the effectiveness of the F@ce ™ is needed, and future research should also focus on interventions that are relevant, accessible and culturally acceptable to those who need them the most, using available and accessible resources within the health care. A future study that would look at a long-term follow-up of using targets as a basis for the rehabilitation to explore maintenance of problem-solving skills after stroke would also provide important knowledge in the further development of the F@ce ™.

ACKNOWLEDGEMENTS

Being a PhD student at the Division of Occupational Therapy, Karolinska Institutet, was a great honour for me and an opportunity that has made great strides in my life and career. I have met very important and highly respected academicians who have provided mentorship and inspiration to further develop my career. Having come from Africa particularly Uganda where occupational therapy programme at the graduate level does not exist, am grateful that I could do from here in Sweden. Through interaction with various people here at Karolinska Institute, I have learned a lot in terms of cultural competences and this experience opens my horizon in understanding human existence and transactional behaviour.

The Division of Occupational Therapy with its wonderful staff has always provided a hospitable environment for me, where everyone is respected and recognized as an important member and such situation offered me a sense of glamour.

I thank the Almighty Lord for blessing me to experience PhD education and to provide me with other wonderful thing in my life. Am very grateful for what I have experienced over the years as a student and am ready to inspire potential others to experience the same because it is worthy.

Several people have contributed and supported me in various ways in the development of this thesis. First and foremost, I would like to thank all participants who provided their knowledge. The participants did not only volunteered to offer their experience but offered their precious time and conducive environment for dialogue.

I would like to specifically thank my main supervisor **Associate Professor Susanne Guidetti** for your excellent guidance and for the enabling environment you provided along the way to reach my targets. You have been involved and supportive and above all you providing your skilful research, knowledge, precious time, experience to my work. I don't have good words to express my sincere appreciation to you for all sacrifices you have made for me but just to wish you good health and more wisdom. You have always provided clear feedback, connections and encouraging words that have kept me with hope and enthusiasm to go extra mile.

I would like to sincerely thank my Co-supervisor **Professor Kerstin Tham**, for your expertise in research and guidance you have always provided. I extend special thanks to you because of your belief in me and above all for opening a horizon for my career. "The history is long" in the same vein words cannot express my gratitude for your contribution to my career development.

I would like to thank **Professor Lena von Koch** for your special wisdom and unique working style. You offered me a good exemplary, selfless ability to share your knowledge, but most of all, your research skills and problem-solving strategies. I have had opportunities to stay at your Hjotnas-Dolarna home doing work with your guidance.

I am very grateful to my co-supervisor **Associate Professor Gunilla Eriksson** who has shared her research knowledge and has been there when I needed her. Sometimes she would wake up early morning and travel from Uppsala to Karolinska Institutet just to share her research experience and support.

Am very grateful to my Mentor **Professor Elly Katabira at Makerere** University who has always provided me with motivating and encouraging research experience. I am grateful for being one of the people that have benefited from your research experiences.

Special thanks to **Mr. Richard Kasiita** the head of Physiotherapy unit Mulago National Referral Hospital for creating the enabling environment for me to recruit participants from the department. Many thanks to **Mr. Ibrahim Bukenya** the head of Stroke Rehabilitation Centre, Wampewo Kasangati for the support during the data collection and for the pieces of advice you provided. The Occupational Therapists who supported me during data collection **Mr. Sulaiman Kigozi, Ms. Juliet Nabateesa and Mr. Julius Ssekyewa** thank you very much. **Mr.Timothy Kalule** for starting up our Facebook page ICT-Stroke Rehabilitation Project Uganda and for all endless transcription of data.

I sincerely thank **Mr. Kato Kimogo Alexander** the executive Secretary of Uganda Allied Health Examinations (UAHEB) who has unconditionally given me study leave and has supported me morally and socially though out my PhD education. I also extend my sincere appreciation to my colleagues at UAHEB who have always carried my share of work when am on study leave; **Mr. Joseph Agondua , Mr. George Fungo, Mr. Ojaki Micloth and Kabasinguzi Veronica** and **other entire staff**.

Great appreciation to **Dr. Rwandembo Wilson Mugisha,** the former UAHEB Board Chairperson who has been a mentor, an advisor, a father, and your contribution to my life and career is immense. I am always humbled by your gift of experience. Had it not have been you, this journey would not have been possible.

I would like to acknowledge and thank **Associate Professor Eric Asaba,** the Head of division of occupational therapy, Karolinska Institutet. Thank you very much for the support you always provided and the good leadership skills. I have always felt at home whenever I have been at the division.

I sincerely and humbly thank my great family, my wife **Mrs. Jane Kamwesiga** who has unconditionally supported me and the family for all these years I have been coming to Stockholm for studies. From the deepest bottom of my heart, I can describe you as a rock, the great wife, great mother, great friend and above all strong woman. Thank you for being there for me and the family.

To my beloved parents, my mother **Mrs. Grace Karindiriza**, thank you very much for your prayers and to the deceased father **Eriezari Karindiriza** for instilling in me the spirit of hard-work and inspiration for education, may your soul rest in peace.

I also extend my appreciation to **Professor Louise Nygard** for the enabling environment for learning. She has always organised Kreativa Konditoriet whenever it was necessary.

I would like to acknowledge **Professor Anders Kottorp** who is also a co-author in one of the papers. Thank you for sharing your great research experience.

Professor Uno Fors and **Ali Ndiwalana** for their technical support, sorting out the problems when needed, without you this should not have been possible.

To the Division of occupational therapy **Staff and Doctoral students**, Karolinska Institutet, I greatly thank you for the hospitality and cordial relationship you always showed me.

This thesis would not have been possible without financial support from Swedish Research Council, Developmental Research (grant number 2014- 28-63), the Swedish Association of Occupational Therapists, the HELD research group at Karolinska Institutet (http://ki.se/en/nvs/ the-held-research-group).

I very much appreciate you generous support

Finally, I thank the Almighty Lord who has enabled me to complete this journey. May your name be praised and magnified forever.

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